

# Folder guide

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## How to use this **guide**

The guide is primarily aimed at staff working in care homes who want to know about the mental health needs of older people in order to improve practice and standards of care. However, a lot of the information will also be useful to other care provider – for example, domiciliary care.

**The information builds on the “3 Ds”:**

**Delirium**

**Dementia**

**Depression**

The layout of the guide is based on the journey of any person entering the care home “world” and therefore you can walk with them as they arrive at the home (“What do I see?”), and continue on their way through Life Story work and finally to end of life care.

The guide cannot give you all the information you need to know but will answer some important questions and help you to think about other things you may need to know, or want to find out.

You do not have to follow the journey through the guide.

There may be particular topics that you want to explore.

The guide can be used by staff in several ways:

**Induction.** New staff will find the information interesting and user-friendly. It gives an overview of issues and some suggestions and will therefore help them gain insight into the mental health needs of older people. It can be broken down into manageable chunks and has “tips” that are easy to remember.

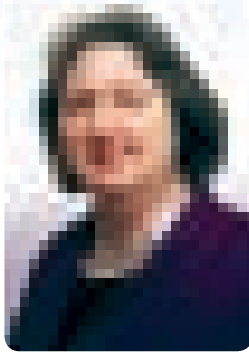
**Supervision.** Specific topics can be explored in supervision sessions using information from the guide. It can be used to introduce new ideas or reinforce learning and development. Staff can research a subject using the guide and other resources. It could be used by staff working towards qualifications.

**Group discussion.** Images in the guide can be used to promote discussion – for example “What is a therapeutic environment?” – what do we need to do to improve?

**Training.** This guide can be used as a resource for training on specific topics like dementia.

**Staff room/resource room.** It will be helpful to keep a copy in a place accessible to staff so that they can “dip into” the guide when they have a spare few minutes. The sections are quite short and so are easy to read over a cuppa!!

Finally...  
please enjoy!



### Acknowledgments

With so many people involved in the creation of this resource, it's difficult to know where to start with some well deserved thank yous!

From the original ideas from my predecessor Nadine Schofield – developer of the first, highly acclaimed Let's Respect pack for hospitals – to a host of others including; Deborah Sturdy, Julie Budd – who has maintained the momentum of the campaigning zeal, Elaine Collins – who has been the golden thread of continuity between us all, our own committed current steering group and the many authors named at the back who have all brought their own expertise to bear on this. Thanks also go to all of the care home staff involved in some of the early research, particularly in the delirium section.

Our aim was to build on the clinical materials of the 3 D's and put the person at the centre of their journey. From coming into the care home and opening the door – “What do I see?” to quality of life, well-being and advice around end of life care.

From the outset the importance of knowing the person, their story and who they are, has been crucial to our approach. The life story section “Do you see me” is a thread running through much regarding quality of life, activities, relationships, spirituality and end of life – **we need to know the person.**

With such challenging work, staff well-being is also extremely important in providing person centred care, which is why we have included the section “Are you OK?”

Produced by experts, this product is unique. Many other tools focus on dementia alone, however, this is equally informative about depression and delirium. Whilst these topics are worthy of a book each, we provide a good overview with guides to further resources if required.

There have been times when we thought this may not come to fruition – it has been a longer journey than we had hoped or expected. I would like to thank Melba Wilson and the Mental Health Equality Team in NMH DU for their support. Also, the belief and patience The Art of Design have had in this endeavour plus Lesley Carter's passion to help us get to the finishing post!

That is enough mixed metaphors for now. We can never thank everyone enough – hopefully most of you are listed on the back!

It has been a challenge and a privilege for me to write and edit. Open and enjoy, we hope it helps in the wonderful care you give.



**Polly Kaiser**

*Consultant Clinical Psychologist*

# Environment

a welcoming place to be



“It is important to create a safe, supportive and social place to be – not one that will disable me.”



## **How am I welcomed in?**

- **What's the front door area like?**
- **Are there fresh flowers around?**
- **How am I greeted?**
- **Do the staff appear friendly and welcoming?**
- **Are they smiling?**
- **What's their appearance?**
- **Are they talking to me?**
- **Are there any interruptions?**
- **Am I introduced to others?**
- **Am I offered refreshments?**

# A welcoming environment



## Transport

The welcome to the care environment will probably start with the journey there.

This could be a mini-bus, a taxi, an ambulance or a car.

It is important that radios and conversations do not exclude any attempts at communication and that you are aware that moving to a new home can be an anxious time.

## External signage

External signage should be clearly visible. No trees or shrubbery covering the sign.

The sign needs to state clearly the name of the care environment and be at a level where people can see this, whether on foot or in a vehicle.





## Garden

**The path from the drop off point should have ramps for wheelchair access.**

The path should be smooth and made of a consistent surface as grids and changes in colour can give the impression of obstacles or holes. Ensure that there are no manhole covers. If manholes are present then they can be lowered and disguised using a recess cover. The path should have distinct edges using colour to provide direction. People will also benefit from boldly coloured handrails that are the same colour as the door.

## Door

**A care environment can have many doors and entrance points.**

There should be a focal point that will be used specifically for welcoming new residents, their families and friends. The entrance should have adequate lighting that will trigger with movement. A welcome sign situated at eye level can offer a homely feel.



## Entrance hall

**Where possible, items that replicate a homely environment should be placed in the entrance hall.**

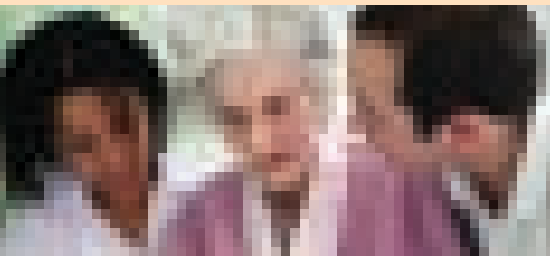
These could be coat and umbrella stands, a clock and seasonal calendar or fish tanks. If possible, a clear and visible route to the toilet should be highlighted using an appropriate toilet sign fixed within vision range. Painting the toilet door a consistent colour throughout the care environment can aid recognition and orientation. For example, if all toilet doors in your care environment are yellow then this may assist recognition of toilets.

# A welcoming environment

## Corridors

Corridors are the routes that a new resident will take and will probably prompt curiosity.

These need to be adequately lit to avoid shadows. The floor covering should be a consistent colour throughout. There should be a clear colour contrast between the floor and the walls. Handrails should also be distinguishable from the wall.



## Staff

Staff should be aware that a noisy and bustling environment could be quite distressing and bewildering for a person new to the care environment.

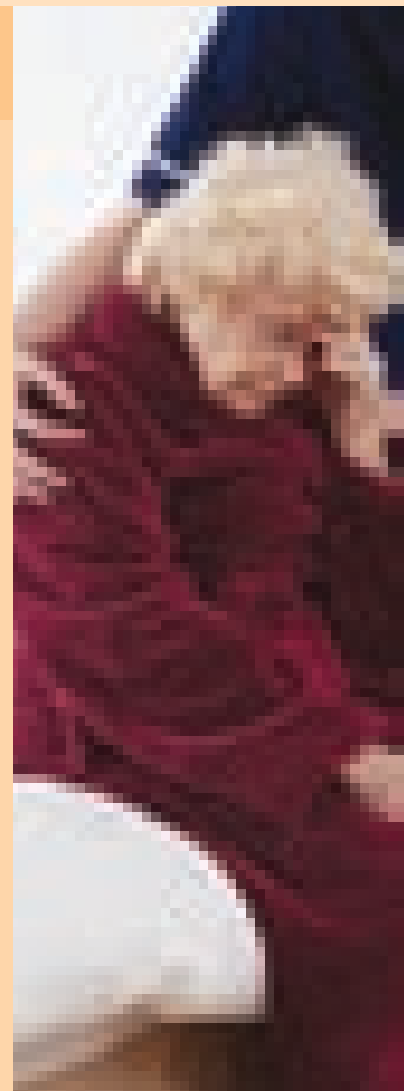
## Bedroom

Introducing a new resident to their bedroom can be improved by ensuring an appropriate sign is located on the door.

This should state the resident's name and be typed using an initial capital letter followed by lower case font large enough to be read by people with visual impairments. Capital letters are not recommended and hand written signs should be avoided if possible. Printing residents' names give a clearer and bolder appearance. For example, **"John Smith"**. The sign should be located within vision range around 130cm off the floor.

The room should be light and airy and the bed should be facing the entrance to the en-suite, if available. The door should be open so that the route to the toilet is easily identifiable. Residents and families should be encouraged to bring photographs and other memorabilia to make rooms

as homely and personal as possible. These are valuable opportunities to integrate Life Story work into creating an environment that is accepted and in some respects created by residents, families and staff together. Staff should also work with residents and use activities to understand past and present interests and achievements – for example, occupations, local scenery, pastimes, films or music. Combining Life Story work with the care environment also provides rich communication tools that prompt meaningful conversations between staff and residents. This is a part of "person centred" or "relationship centred" care.



# The dining room experience, nutrition and hydration



*Food that warms the heart.  
Edna's favourite time of day.*

Creating the right care environment is essential for living well with dementia. Fundamentally, the importance of eating and drinking is to maintain a healthy and balanced body. In addition, meal times are an important feature for people as they provide opportunities for social interaction. Meal times can pose both positive and negative end results. For example, a time to chat, be jolly and enjoy food and drink, or a time where a sense of inadequacy can lead to feeling embarrassed, frustrated or isolated, often leading to withdrawal. Understanding what meal times were like for the person before they came into care could help you create a more familiar and reassuring eating and drinking experience.

## Meal times are an important feature for people living in care homes as they provide opportunities for positive social interaction

The dining room should be clearly signed and the walls decorated with images of food to help residents understand where they are and to stimulate appetite. The manner in which the table is set can also help residents improve and maintain their independence. Rather than using white or patterned table cloths and napkins, use bright and contrasting plain colours to create distinction. White crockery often hides paler foods such as rice pudding or mashed potato. If the food is not eaten it can be commonly misunderstood as residents not being hungry. Brightly coloured, contrasting crockery with large rims and deep insets can help food recognition, assist with getting the food onto cutlery and overcome feelings of embarrassment.

Residents benefit from meal times being protected. This means no phone calls or private conversations should take priority. Interactions with residents should be the focus. Ensure appointments are made outside meal times and that under no circumstances should a resident be removed from the dining room once they have commenced their meal. Sometimes relatives may want to help their family member's meal times. It is important that this is respected but that meal times are kept person-focused.

- **Maintain and encourage skill sets**
- **Promote independence**



# What do I see?

## A good example

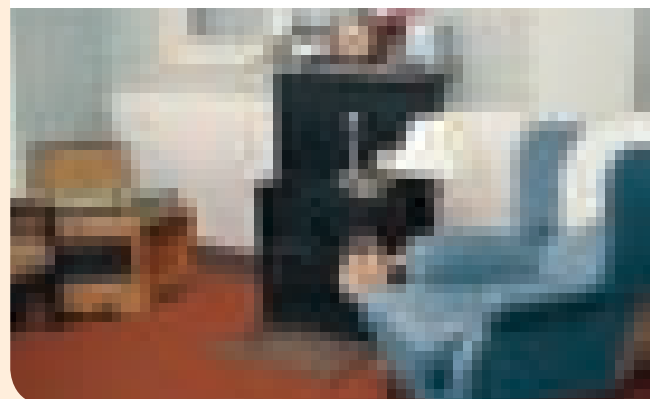
*"As I walked into the care home, I was immediately made welcome"*

- No waiting at the door or waiting for staff to open it.
- A reception desk with lots of information on it and a member of staff ready to assist me.
- I saw people with smiling faces and a friendly approach.
- People who appeared in control, comfortable and confident.
- Everyone was happy to talk.
- There was no bad odours, only a sense of "home" and smells of cooking and furniture polish.
- Walking round, I saw people who were communicating with each other, chatting and engaged.
- I saw a sense of calm with no shouting or signs of distress.
- I saw people occupying spaces with different activities.
- There were groups of people enjoying time together and being pro-active in initiating conversation.
- I saw lots of clues and prompts for people to follow.
- As I looked more closely at what was happening, I saw the activities were:
  - People talking to their families.
  - Reading books and newspapers.
  - Looking at photographs.
  - A carer knitting while being watched by others who engaged in conversation.
  - Normal daily activities such as washing up.
  - Artwork.



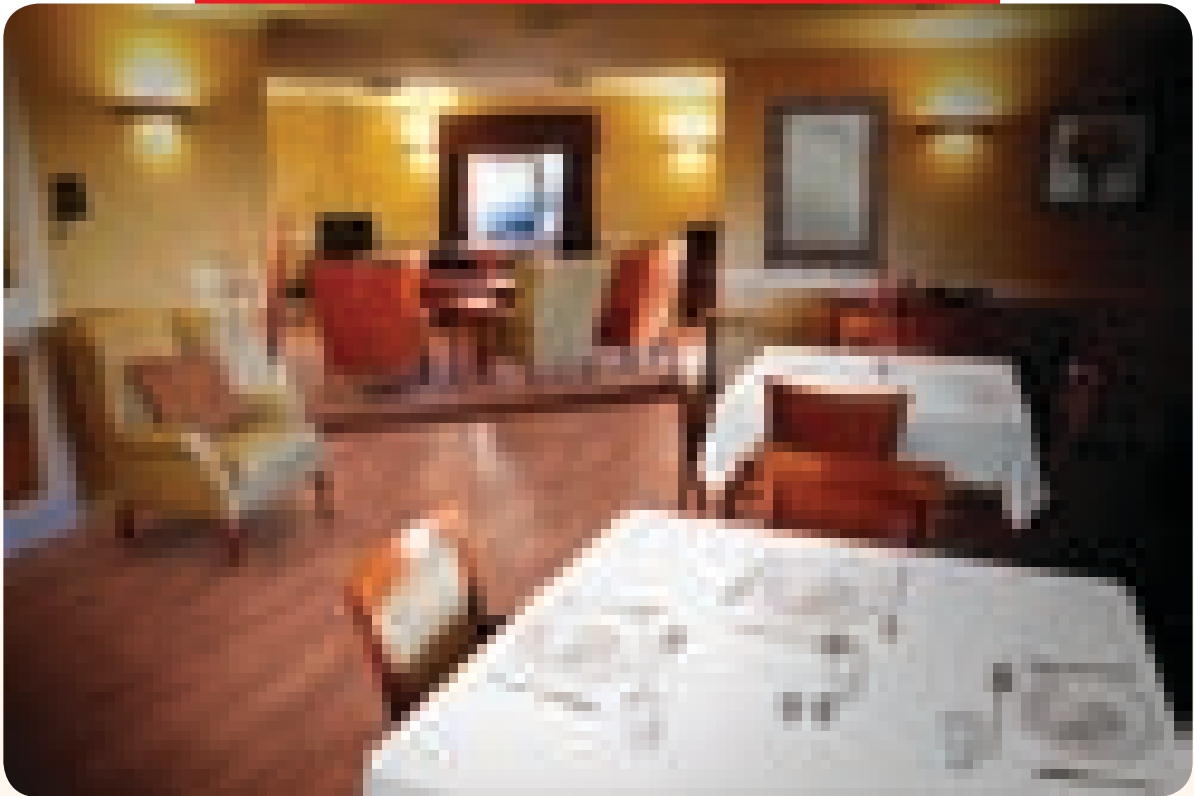
## What did I see?

*I saw a care home where I would be happy for my parents to live and where I would be happy to live. I saw a care home where everyone was seen and valued.*



# What do I see?

## 1 - Confusing interior environment



## 2 - Supportive interior environment



# What do I see?

**Image 1** shows some of the common environmental features that can cause significant challenges for people living with dementia.

**Image 2** shows how some of the common features can be changed to assist people with everyday activities.

It is often assumed that people living with dementia mostly have problems with their memory.

**While memory problems are a major symptom of dementia, people living with dementia also experience changes in the ways that they see or visualise their surroundings.**

- The rooms and corridors should be adequately lit. As you can see in **image 1**, the room is quite dark. This can make it difficult to see, presents problems for orientation and obstacles may hinder people walking around.
- For people who experience visual difficulties, a change in surface colour can give the impression of a step or change of depth. This is because, in addition to the normal aging process, some areas of the brain that process information may have been affected by dementia.
- When asking people to move over carpet strips or onto a change of floor surface, the perceived step or depth can cause anxiety. If possible, maintain a constant colour throughout. As you can see, **image 2** has a constant floor colour and presents a confident way into the lounge area.
- Shiny surfaces can give the impression of water. **Image 1** shows how the shine may present significant challenges due to, perhaps, a fear of slipping.
- Due to the changes in how the brain processes information it is important to think about how we can use colour to improve recognition. For example, in **image 1** the chairs are a similar colour to the floor.
- In **image 2** the chairs are a colour that contrasts with the floor. This helps the person to see or visualise that there is a chair and may improve confidence in sitting down.
- Similarly, white table cloths, white napkins and white crockery can blend into one mass of colour making it difficult to distinguish between the plates and the table cloth.

## What do I see?

- Look carefully at the white crockery. Each plate has a portion of potato on it. Look now at **image 2**. Here we can see how the use of coloured crockery helps make the food stand out much more clearly.
- In **image 1** the beakers are filled with water. You can see how it would be easy to overlook that there was a drink on the table. If possible use coloured beakers. Squash or cordial can also assist with recognition, as in **image 2**.
- Mirrors are obviously useful, but for people living with dementia, they can be frightening or disturbing because sometimes the reflection may not be recognised. It is common for reflections to be mistaken for strangers, imposters or maybe a family member.
- Instead, culturally relevant images can be used. As you can see in **image 2**, we have used pictures of food to draw attention to food in the dining area. This can help with way-finding, orientation, a sense of location and perhaps may stimulate appetite.
- It is common to put pictures of landscapes and flowers on walls as means of decoration but these types of images do not stimulate interaction or conversations. Pictures of people, places or objects that are meaningful can provide many more opportunities for discussion or distraction, particularly in difficult moments.
- Finding out about people's life history and matching these with appropriate images could form part of your activities schedule. This can be further improved by using objects that reflect your resident's past. As you will see, we have put an old fashioned sewing machine on the sideboard. A seasonal clock showing the time, day and month may offer reassurance.

**Remember, these ideas will help everyone, not just people with dementia.**

## Top ten tips for helping someone settle in a care home

- Avoid the person arriving at busy times i.e. lunchtime.
- Ensure that a member of staff is available to meet them on arrival.
- Try to get to know the person as much as you can before they arrive i.e. life history, dietary needs.
- If possible, have personal belongings in the room so the residents can identify with familiar things.
- Consider cultural needs.
- Allocate one member of staff to the person to help them settle in and identify someone they are familiar with.
- Introduce people to each other.
- Ensure appropriate signage is available to aid orientation.
- Ensure there is a familiar face to greet the person when they arrive.
- Ensure a thorough care plan and medical history is documented and, if possible, some Life Story work already completed.

# Quality of Life

BY EDITH BROOKING

*Someone who listens*

*Someone to talk with*

*Kindness and understanding*

*Someone to laugh with*

*'Me' to see 'me' a lot*

*I like to be liked*

*I like to please*

*I like to know what pleases you*

*So that I can pass it on to someone else*

*Doing things, loving people*

*Letting them know you are thinking of them,*

*I like to see the light come into their face because I have*

*said something that really makes them happy,*

*...because I had so much unhappiness as a child*

*It is not so much about what people do but about relationship.*

# Resources: Environment

## ON LINE RESOURCE LINKS

- **PSS Dementia Centre** provides excellent information and support for people, their carer's and health professionals.  
**[www.dementiacentre.com/](http://www.dementiacentre.com/)**
- For useful downloads  
**<http://dementiacentre.com/download.php?list.6>**
- **The Kings Fund**. Enhancing the healing environment.  
**[www.kingsfund.org.uk/current\\_projects/enhancing\\_the\\_healing\\_environment/](http://www.kingsfund.org.uk/current_projects/enhancing_the_healing_environment/)**
- **Find Dementia Signage** offers a range of signage and other equipment suitable for care home environments.  
**[www.findsignage.co.uk/](http://www.findsignage.co.uk/)**
- **Alzheimer's Society** provides a range of books and factsheets that you may find useful.  
**<http://alzheimers.org.uk/>**
- **Age UK** offers a wide range of useful information.  
**[www.ageuk.org.uk/](http://www.ageuk.org.uk/)**
- **Rackety's** specialist clothing provides up to date and trendy functional clothing.  
**[www.disabled-clothing.co.uk/index.php](http://www.disabled-clothing.co.uk/index.php)**
- **Medoris Care** offer a wide range of textile products aimed at improving quality of life.  
**<http://www.medoriscare.co.uk/>**
- **Dr Gayle J. Booth**, offers in depth reviews on inclusive practice within people's own homes, care homes, hospitals, day centres, public spaces that improve the physical and social environments of people living with a diagnosis of dementia, their carers, families and professionals.  
**[www.gaylejbooth.com](http://www.gaylejbooth.com)**

# What's my Life Story?

Who am I?



“Someone who listens.  
Someone to talk with.”

# What is Life Story work?

**“The pastime of ‘scrapbooking’ – making photo albums and sharing memories – is a common, everyday activity, which many people do to celebrate birthdays and anniversaries. It is part of the ‘remembering’ practices we all engage in throughout our lives. We all have a story.”**

[www.lifestorynetwork.org.uk](http://www.lifestorynetwork.org.uk)



**“It can make a huge difference to the relationship between staff and the people they care for.”**

**Sir Michael Parkinson**

‘My year as a dignity ambassador’

Life Story work is a process. It is not just a form to be filled – but a process of “getting to know” a resident.

It is not just about looking back on the past but also understanding current hopes and future dreams such as going back to church or seeing family etc.

It is usually done on a one-to-one basis.

It does not set out to resolve past problems or present ones. It is not therapy – even if it is therapeutic.

It does not have to result in a “book” – It can be sheet of A4, a timeline or some pictures in a scrapbook.

## **The aim of Life Story work**

Life Story work aims to improve the quality of life and wellbeing of people by enabling them to document and share their Life Story in whatever way is best for them. Examples include written script, photographs, a computer file, memory boxes, audio tapes or DVDs. It is their story and puts them firmly in the centre. It is a vehicle for purposeful and respectful communication between the individual concerned and staff who are working with them to provide personal care and support.



## Why is it important?

### For a resident?

- To feel valued.
- To promote self esteem.
- To retain and regain a sense of individuality and identity.

### For a relative?

- It helps with peace of mind as others will have a sense of knowing their relative/loved one.
- Enjoyable to do.
- Point of reflection and conversation.
- Loved one is seen and remembered as a person.
- Legacy for others e.g. children, grandchildren.

### For staff?

- To know the person better.
- To aid communication.
- To understand behaviour (particularly if challenging).
- To tailor care to person's needs.
- Job satisfaction.

**Eric** would lie under any tables he could find and would become aggressive and resist all attempts to get him to come out. When care staff looked at his Life Story they learnt he used to be a car mechanic. He felt as if he was being stopped from doing his work – and understandably become angry.

#### What would you say to Eric ?

Possible answers: “Come on Eric – it’s break time/ lunch time. This job is finished – you need to eat before your next job.”

**Joan** would wake up early and walk around and around the unit. She would eventually sit at a table and bang and bang until she was given a cup of tea. Later carers found out that she used to walk her dog every morning and come home and have a milky coffee with 2 sugars – she did not like tea.

**Martha** loved classical music. She particularly liked Beethoven and that would calm her.

**George** loved art – care staff could sit with him and look at books with paintings in. They knew he was interested in that and he would smile.

**Alice** would sometimes not want to get undressed at night time. Her husband explained to staff that this was because during the war she would sometimes keep her clothes on in case she had to go to the air raid shelter.





HAZEN



BIL'S

# Benefits of Life Stories for Carers

## A daughter's perspective

Dad was 84 and living alone with dementia when offered the opportunity via the Oldham Life Story Group to “produce” his Life Story with Chris, then a trainee clinical psychologist.

Although he was severely cognitively impaired he welcomed the opportunity to talk about his childhood and working life in particular. He relished showing his portfolio of drawings from his career to anyone who was interested, as well his many watercolours. He talked about his many hobbies and love of outdoors so took Chris on his daily walk to show him.





## ...they asked other families if they could do life stories with all the residents.

Dad was very pleased to have someone interested in his life but said why me? I suggested that he'd had a very interesting life and other people might be interested in it. He clearly felt valued and proud of his "book", so much so that he lent it to a friend at his weekly dance before it was even finished.

When Dad agreed to move to a permanent care home near me the book was used by all the care staff so that they got to know him quickly. This helped him to settle into the home and for the staff to know his interests. He proudly showed his book to all the other residents too.

I continued to update the book, with Dad's permission and involvement.

The care home found this so useful that they asked other families if they could do life stories with all the residents.

From my perspective I was reassured to know that the staff had a lot of personal information about Dad and this helped them formulate and review his care plan. It reinforced for me that he was treated with respect and dignity as an individual.

At Dad's funeral the Life Story book was used to help the minister better understand Dad as a person. It is a lasting legacy for the family.

*Jean Tottie E: jean.tottie@btinternet.com*

# Ways of getting to know me

**Feelings come first rather than facts.**

- Where were you born?
- What part of the country do you consider home?
- What is the place that you like or dislike the most?
- What did your parents do for a living?
- Where did you go to school?
- Did you like school?
- What subjects did you like the most?
- Where did you go on holiday or for a day out?
- Did you have any pets?



# Life History Notes



- What makes you laugh?
- What would your idea of a real treat be?
- Tell me about someone who you really admire.
- Tell me about something in your life that you are really proud of.



# Resources: Do you see me?

## ON LINE RESOURCE LINKS

- [www.nmhdu.org.uk](http://www.nmhdu.org.uk)
- [www.lifestorynetwork.org.uk](http://www.lifestorynetwork.org.uk)
- Portrait of life [andrea.trangmar@swyt.nhs.uk](mailto:andrea.trangmar@swyt.nhs.uk)
- Bradford Dementia Centre Worcester  
[www.bradford.ac.uk/health/dementia/](http://www.bradford.ac.uk/health/dementia/)

- ***This is me*** is a form about the resident with Dementia.  
It is to be completed with the assistance of a professional carer.

***This is me*** is intended to provide professionals with information about the person with dementia as an individual. This will enhance the care and support given while the person is in an unfamiliar environment. It is not a medical document.

It can be downloaded from:

[www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=849](http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=849)

- ***Life Story*** is a form about the resident with Dementia.  
It is to be completed with the assistance of a professional carer.  
[www.lifestorynetwork.org.uk](http://www.lifestorynetwork.org.uk)

# My health

recognising changes in my health



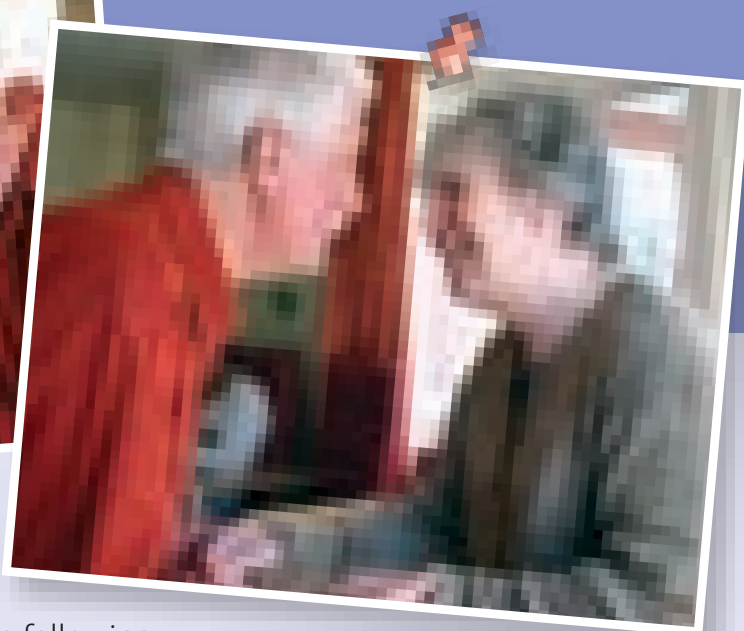
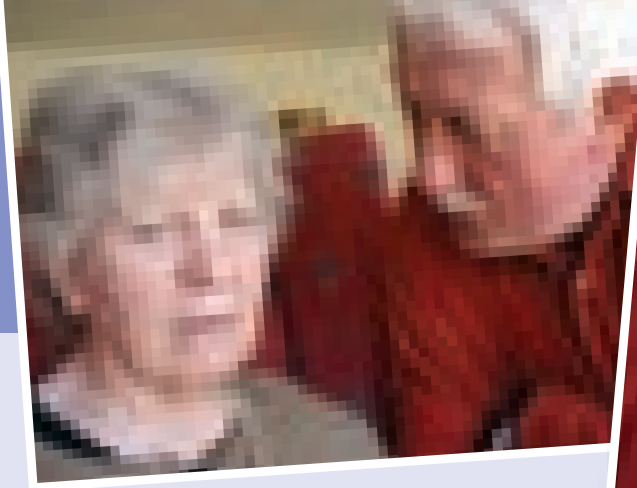
The next section deals with the three main areas that affect people's mental health and wellbeing.

**“To know if someone is not well, we first need to know what well looks like.”**

## Ten Key Messages

# ...about mental health and wellbeing in later life

- 1** Everyone has mental health in the same way that everyone has physical health. Some people may have better mental health than others, and it can change over time.
- 2** Mental health is not the same as mental illness – mental health is as important as physical health; it is your spiritual and emotional wellbeing.
- 3** Our mental health is made up of many things, such as our thoughts, feelings, beliefs, values, hopes and fears, and life experience – what we are conscious of, as well as our subconscious, makes us who we are.
- 4** Mental health is influenced by individual and internal thought processes as well as external factors: relationships, work/income, families, where we live, communities, etc.
- 5** Good mental health is not the same as happiness. Mental “wellbeing” is another way of describing it. It is only natural to experience things in life which upset us or make us feel bad in different ways and wellbeing, or good mental health, enables us to cope and thrive across the full emotional spectrum of good and bad feelings, worries and sadness within everyday life, relationships and communities.
- 6** People with good mental health can still experience mental health problems (such as through a bereavement) though poor mental health can mean greater vulnerability to mental illness and slower recovery from any life incidents.
- 7** People with mental health problems and conditions such as dementia still have mental health and can benefit from activities and interventions which promote mental wellbeing (see point 9).
- 8** Problems such as depression and dementia are not an inevitable part of growing old (all the evidence shows that most older people will not get depression or dementia). But growing older does increase the risk of becoming depressed or getting dementia.



**9** Evidence from a national inquiry into mental health and wellbeing in later life identified the following factors as being particularly important in relation to promoting good mental health in later life:

- Not experiencing ageism or age discrimination.
- Having opportunities to participate in meaningful activities.
- Having positive social relationships.
- Maintaining good physical health.
- Having enough money.

**10** Evidence also shows that an older person's mental health can be at particular risk (especially if they have experienced mental health problems in the past) when the following occurs:

- Onset of physical illness or significant deterioration in physical health.
- Bereavement or loss (which can include retirement, loss of role, status or income).
- Becoming a carer or significant changes in caring responsibilities (especially for a spouse or partner), or becoming more care dependent (e.g. moving into a care home).

## Questions to consider

- What can you do to help promote good mental health and wellbeing among the older people you work with?
- Are there older people you work with whose mental health may be at particular risk?
- Can you tell the difference between good mental health and wellbeing and poor mental health?
- Can you identify what makes you feel happy, fulfilled and valued?
- What do you do or how do you cope if you experience problems in your life?
- How could you help the people you work with to manage their feelings?

# Five Ways

## ...to wellbeing and the mental health of your residents

### 1 Connect

With the people around you. With family, friends, colleagues and neighbours. At home, work, school or in your local community.

In your work, connect with residents in your care. Say hello when you arrive and goodbye when you leave. Ask them how they are. Use Life Story work to talk to them about things they have experienced or that interest them.

Think of these as the cornerstones of your life and invest time in developing them. Building these connections will support and enrich you every day.

### 2 Be active

Go for a walk or run. Step outside. Cycle. Play a game. Garden. Dance.

In your work, help residents to remain physically active at a level that is safe and appropriate for them. Discuss how this can be done with the home's activities co-ordinator.

Exercising makes you feel good. Most importantly, discover a physical activity you enjoy; one that suits your level of mobility and fitness.

### 3 Take notice

Be curious. Catch sight of the beautiful. Remark on the unusual. Notice the changing seasons. Savour the moment, whether you are on a train, eating lunch or talking to friends.

In your work show interest in what a resident is talking about. Help them experience and see different things. Point out to them things that are nice or interesting to experience.

Be aware of the world around you and what you are feeling. Reflecting on your experiences will help you appreciate what matters to you.

### 4 Keep learning

Try something new. Rediscover an old interest. Sign up for that course. Take on a different responsibility at work. Fix a bike. Learn to play an instrument or how to cook your favourite food.

In your work, support residents to remain active and to be able to participate even if it's just helping lay a table or wash something up. Use Life Story work to find out what a person finds interesting or might want to do. Discuss how this can be done with the home's activities co-ordinator.

Set a challenge you will enjoy achieving. Learning new things is fun to do and will make you more confident.

### 5 Give

Do something nice for a friend, or a stranger. Thank someone. Smile. Volunteer your time. Join a community group. Look out, as well as in.

In your work, remember important anniversaries for residents. Show how much you value them as individuals by being positive and giving them the same respect you would give your own family.

Seeing yourself, and your happiness, linked to the wider community can be incredibly rewarding and will create connections with the people around you.

# What is delirium?

It's also known as “Acute Confusional State”

- It's a **change** in a person's mental state **over a few hours or days**.
- People often become **more confused** than usual.
- People with delirium typically have difficulty paying **attention** to what is going on around them.
- They may not seem like their usual self, for example they may be **more agitated** or **more drowsy and lethargic than usual**.
- It tends to **vary** during the day – people may be confused at some times and seem their normal self at other times.
- It's a sign that **something is wrong**.
- **It needs to be investigated!**

Delirium can last for **weeks** and even **months** in older people

# Why is it important to

**spot it?**

- Delirium is often mistaken for worsening dementia or “just old age”.

## But think!

- It's a sign that a person may be physically ill.
- Delirium can cause lots of problems:
  - Delirium can be distressing for the person, their visitors and the staff caring for them.
  - A person with delirium is more likely to go into hospital... and to stay longer.
  - They may lose some of their abilities.
  - ...and have an increased chance of dying.
- Delirium needs to be treated urgently.
- Delirium is **reversible**.
- ...and **delirium can be prevented!**

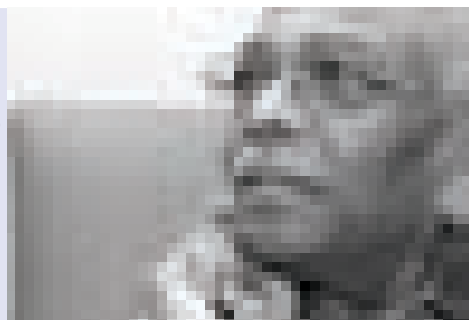
# DELIRIUM

Acute confusion is a sign that someone is physically unwell

## 1 SPOT IT

- Sudden change in behaviour?
- More confused over the past few hours or days?
- Confusion varies at different times of day?
- Difficulty in following a conversation?
- Rambling and jumping from topic to topic?
- More sleepy or more agitated than usual?

**IF ANY ANSWERS ARE “YES”  
IT COULD BE DELIRIUM.  
IF IN DOUBT CHECK IT OUT.**



“My mind seemed to have gone...  
I was in a different world...  
I didn’t want them thinking I was potty”

## 2 TREAT IT

Remember the six common causes of Delirium: “P.I.N.C.H. M.E”!  
**PAIN • INFECTION • CONSTIPATION • (DE)HYDRATION  
MEDICATION • ENVIRONMENT**

## 3 STOP IT

### EXPLANATIONS AND REASSURANCE

Introduce yourself and explain what you are doing.  
Be calm and patient, avoid being confrontational.

### REORIENTATION

Remind the person of the time, date or season.  
Set clocks and calendars to the right time and date.  
Turn down noisy TVs or radios.

### LOOK AFTER PHYSICAL NEEDS

Drinking, eating, toileting, sleep time, prevent falls.  
Check for signs of infection or pain.



# Risk factors

Dementia—people with dementia are FIVE times more likely to get delirium.

There are many things that mean a person is more at risk of getting delirium.

The most common risk factors are:

- **Older age**
- **Falls**
- **Disorientation**
- **Poor vision or hearing problems**
- **Poor nutrition**
- **Urine catheters**
- **Illness**
- **Immobility**
- **Lack of stimulating activities**

# Common causes

Look out for  
**PINCH ME**

**P**ain  
**IN**fection (e.g urine infection, pneumonia, infected pressure sores)  
**C**onstipation and poor nutrition  
De **H**ydration  
**M**edication  
changes to the **E**nvironment, causing disorientation

Also watch out for sensory impairment,  
sleep disturbance and immobility.

Another common cause is withdrawal –  
(e.g. from alcohol, or from prescribed drugs if stopped too quickly).

In older people you may need to look for  
more than one cause of delirium

# How do I spot delirium?

**Ask yourself...** (or someone who knows the person):

- Have you noticed a **sudden** change in the person?
- Do they seem **more confused** than usual over the last **few hours or days**?
- Does the confusion **fluctuate** during the day – sometimes the person seems very confused, but other times not too bad?
- Are they more confused than usual at **night**?
- Do they seem to have more difficulty than usual focusing attention?
- Do they find it hard to follow a conversation or seem easily distracted?
- Do they seem to be rambling or to jump from one topic to another?
- Does their thinking seem **more disorganised** than usual?
- Does the person seem **more agitated OR more sleepy** than usual?

**If the answer to ANY of these questions is YES, you should THINK OF DELIRIUM.**

Other symptoms may include:

- **Memory problems**
- **Disorientation**
- **Hallucinations**
- **Delusions and**
- **Change in sleeping pattern.**

**If a resident seems to have changed suddenly but you are unsure why, it is safest to assume delirium and check to see if there is a physical cause.**

**REMEMBER TO  
THINK OF DELIRIUM  
IF SOMEONE IS  
MORE SLEEPY THAN  
USUAL**

# What can I do?

## **Delirium CAN BE PREVENTED.**

Preventing delirium is more effective than treating it.

**Anything that can be done to reduce a cause or a risk factor could help prevent delirium.**

### **Here are some examples:**

(but these are by no means all the things you could do!)

- **Reduce disorientation**
  - Have clocks and calendars in each room, and have clear signs in the home...
  - AND make sure they are displaying the correct information!
  - Encourage residents to take part in activities that will stimulate their minds.
- **Reduce dehydration/constipation**
  - Encourage residents to drink more fluids throughout the day.
- **Nutrition**
  - Encourage residents to eat well.
  - Pay attention to good mouth care.
  - If people have dentures, ensure they fit properly (if people are in pain they won't be able to eat).
- **Avoid infection**
  - Look for and treat infection.
  - Avoid unnecessary catheterisation.
- **Medication**
  - Being on too much medication (polypharmacy) may cause problems.
  - Make sure that prescriptions are reviewed regularly by the GP, practice nurse or pharmacist.

- **Encourage mobility**
  - Regular movement helps improve physical and mental health.
  - Encourage residents not to sit or lie still for longer than 30 minutes at a time.
  - Even when they are sitting, they can be encouraged to move e.g. by making circles with the ankles, clenching and releasing fists, wiggling toes.
  - Playing music to move to can help!
- **Glasses and hearing aids**
  - Encourage people to wear their glasses (and check that they are clean!)
  - And to wear their hearing aids (and check that they work).
  - Check for ear wax if they seem to be having more problems hearing.
- **Reduce sleep problems**
  - Encourage a good night's sleep.
  - Minimise napping and encourage them to take part in stimulating activities during the day.
  - Provide a relaxing bedtime routine and reduce noise at night.
- **Improve pain control**
  - Check if the resident has any discomfort or pain.
  - Not everyone that is in pain will be able to tell you – look for non-verbal clues e.g. repeated rubbing, grimacing, distress.
  - Make sure pain management is adequate, appropriate and given.

**THESE ARE ALL EXAMPLES  
OF PERSON-CENTRED  
AND GOOD QUALITY CARE**

# Delirium “Treat it”

Spotting delirium and treating the cause **EARLY** is the most important thing you can do.

## Remember, delirium needs urgent action!

- You may need to call for specialist help to investigate and treat it.

## Look for the cause and treat it.

### For example:

#### Medication

- Has any new medication been started recently?
- Have any medications been stopped suddenly?
- Sometimes if a person becomes unwell, even medication they have been on for a long time may cause problems.

#### Infection

- Are there any pressure sores?
- Do they have signs of a urine or chest infection?

**Remember, if a resident does  
not seem their usual self,  
think delirium!**

**IF IN DOUBT, CHECK IT OUT**

**Identifying and treating the cause of DELIRIUM is the most important thing you can do to manage it. But several other things may be useful in helping someone with delirium...**

### **Offer explanations and reassurance**

- Speak calmly and avoid being confrontational.
- Introduce yourself and explain what you would like to do.
- Give clear, simple directions, one at a time to avoid frustration and over-stimulation.
- Explain to the person that they may be more confused because they are unwell at the moment.
- Encourage visits from relatives and friends – it can be helpful to have familiar people around.

### **Help with reorientation**

- Encourage the person to wear their glasses if needed, and check that the glasses are clean!
- If the resident uses a hearing aid, encourage them to wear it and check that it is turned on and working properly.
- Provide clocks, calendars and orientation boards making sure that they show the correct time and date and information.
- Remind the person of where they are.

### **Environmental stimulation**

- Prevent over-stimulation by making sure the area the resident is sitting in is not too hectic. Turn down the TV or radio, and make sure there are not too many people about.
- Prevent boredom or feelings of isolation. Make sure the environment is not under-stimulating. Leaving the person with absolutely no distraction may make them more withdrawn and confused. Familiar items can help to comfort.

### **Encourage a good sleep routine**

- Discourage daytime napping.
- Avoid caffeinated drinks after teatime.
- Offer warm, non-caffeinated drinks at bedtime (e.g. milk or herbal tea).
- Provide a relaxing environment and a regular bedtime routine.

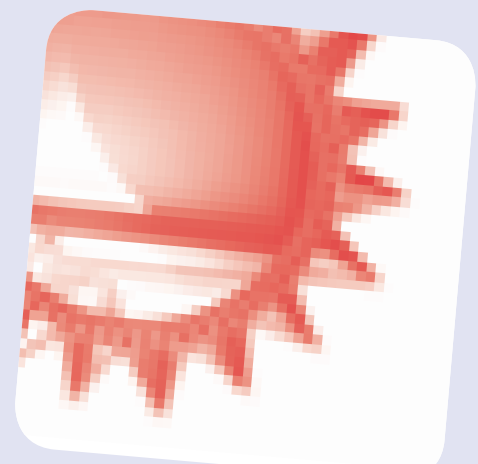
# People with delirium display behaviour that may be difficult to manage

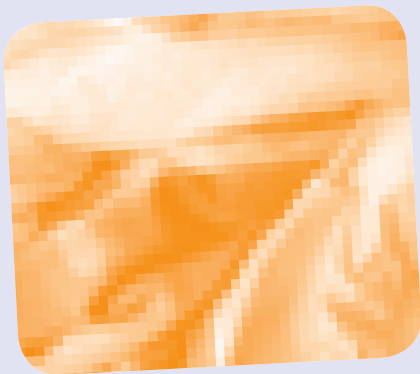
## If a person is agitated:

- Talk to the person in a calm manner, avoid being confrontational.
- Try to find out the reason why the person is behaving unusually e.g. they may need the toilet, feel thirsty, or be in pain.
- If the person is reluctant or distressed, stop and think: could what you are doing wait until the person is more settled?
- Try distracting the person to discourage behaviour that could distress others e.g. if someone is going into other people's rooms and going through their clothes, you might give them a box of clothes to sort through.

## If a person is rambling, hallucinating or seems to have strange beliefs you could:

- Focus on the emotion and acknowledge the feeling in what the person is saying rather than content (e.g. "I feel frightened of soldiers coming." You could respond "You feel frightened? Can I help you?")
- Avoid collusion.
- Use distraction.
- Remove things that are being misinterpreted (e.g. piles of clothes or mirrors).





Medication is sometimes considered as a way of managing distress or behaviour.

Medication needs to be used carefully. It could worsen confusion, over-sedate and increase the risk of falls, or cause other side effects.

Usually, one-to-one care is more helpful.

### **Look out for increased risk of falls**

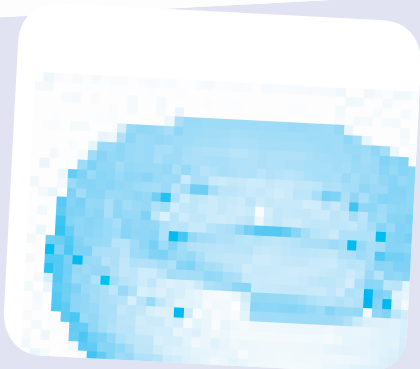
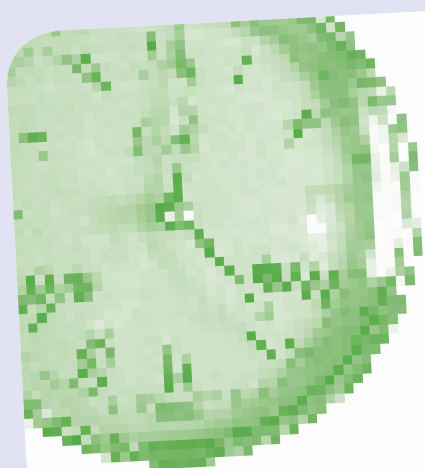
- A person who has delirium may wander more or be more unsteady on their legs, especially if they have been given sedating medication.

### **Make sure they have enough to eat and drink**

- A resident who has delirium may need extra help to eat and drink enough, or small portions of food to tempt them to eat.

### **Toileting**

- If a person is confused they may have trouble recognising that they need to use the toilet or may not be able to tell anyone in time.
- It may help to encourage them to use the toilet every two or three hours.



# After the confusion...



It is important to give the person a chance to talk about their experience if they want to. Many people who have had delirium worry that it might be a sign that they are going mad or getting dementia.

Explaining the reasons for their confusion can help them to understand their experiences better and reduce their worries.

Relatives and friends may need information to help them understand what happened to their loved one, and may also be in need of reassurance and support afterwards.

## How would you feel?

This is an experience reported by someone who has had delirium.

“You are lying in bed. When you look to the side of the bed, you can’t see the floor – instead there is a big drop. Someone you don’t recognise tells you that you need to get up, and tries to help you to get out of bed. You know that if you get out of bed you will fall, but she won’t listen to you. She keeps on telling you that there is a floor, but you can see quite well that there isn’t.”

## How would you feel?

Something similar happened to Lucy. She said...

“But it was very frightening love, that was the worst thing love, seeing them disappear and being told that I could step out of bed when I knew I couldn’t.”

“Well, I still think about it and get frightened.”

# George behaves oddly

**George has been a resident in your home for the last two years. He has been diagnosed with Alzheimer's disease.**

He is usually quite talkative, though often shifts the conversation to his days as an electrician's apprentice and frequently seems to think that it is the 1960s. He asks where he is more often, and has been wandering at night. This has been going on for several months.

In the last few days he has been incontinent of urine (unusual for him), and has been shouting out, especially at night. Last night you found him trying to dismantle a plug in his bedroom.

One of his visitors mentions to you that he has said that he believes staff are trying to poison him.

## What could you do?

- Look for signs of infection – test urine with a dipstick / take his temperature.
- Remind George of who you are, where he is, and the time of day when you interact with him. Explain what you would like to do before doing it (e.g. taking him to the toilet). Be patient.
- Find out if George trusts some staff more than others and get them to be more involved with his care, especially in encouraging him to eat and drink. Maybe you could ask his visitors to encourage eating and drinking.
- Try to find out why he is shouting at night – what is he trying to communicate?
- Offer distractions e.g. Lego if he wants to take things apart – it's less dangerous than dismantling a plug!
- Consider medication only if other measures do not settle his agitation – medication could worsen his confusion or over-sedate him and increase the risk of a fall, or cause other side effects.
- Give explanation and reassurance to visitors.



## Dementia or delirium?

**What are the signs that George's Alzheimer's disease is worsening?**

- Increasingly asking where he is.
- Night time wandering.
- Noticed over several months.

**What are the suggestions that he might have delirium?**

- Behaviour change over last few days – shouting out (acute onset).
- Worse at night (fluctuating).
- Delusions – George believes staff might poison him.

**What might be the cause of delirium?**

- Incontinence may suggest a urine infection.

**What risk factors should you consider?**

- Dementia is a risk factor – people with dementia are five times more likely to be acutely confused.
- George may be eating and drinking less if he thinks staff are trying to poison him, therefore there is a risk of dehydration and / or constipation.
- Risk of falling (especially if George is wandering at night and is now more confused).

# Delirium, Dementia & Depression

## Can you tell them apart?

Delirium can be difficult to tell apart from other common problems in older people – dementia and depression. It can be especially tricky if someone has delirium as well as having dementia, but this is very common. In fact, someone with dementia is five times more likely to develop delirium than someone without dementia.

The table should give you some pointers for distinguishing between delirium, dementia and depression.

**REMEMBER, IF IN DOUBT, FIRST CHECK FOR A PHYSICAL CAUSE**

	DELIRIUM	DEMENTIA	DEPRESSION
Onset	Sudden (hours to days)	Usually gradual (over months)	Gradual (over weeks to months)
Alertness	Fluctuates – sleepy or agitated	Generally normal	Generally normal
Attention	Fluctuates – difficulty concentrating, easily distractable	Generally normal	May have difficulty concentrating, easily distractable
Sleep	Change in sleeping pattern (often more confused at night)	Can be disturbed – night time wandering and confusion possible	Early morning waking
Thinking	Disorganised – jumping from one idea to another	Problems with thinking and memory, may have problems finding right word	Slower, preoccupied with negative thoughts of hopelessness, helplessness or self depreciation
Perception	Illusions, delusions and hallucinations common	Generally normal	Generally normal

# Q&A Delirium

## How can I help prevent problems with medication?

- Review the medication regularly (ask the GP or pharmacist).
- Make sure residents take their medication. Stopping suddenly could bring on withdrawal symptoms.
- Make sure the residents don't take someone else's medication.

## How can I help prevent dehydration?

- Make sure water or juice is within easy reach all the time, in a cup they can manage.
- Prompt the resident to drink a little every hour – e.g. three swallows of water.
- If a resident is reluctant to drink find out why – e.g. they may be worried about wetting. Stress the importance of drinking and prompt them to use the toilet frequently to minimise the chance of accidents.

## How can I help prevent disorientation?

- Make sure residents use their glasses and hearing aids. Check they are clean and working!
- Make sure that clocks, calendars and orientation boards can be easily seen and that they display correct information!
- Ensure adequate lighting.
- Encourage a good night's sleep; minimise daytime napping if night time sleep is a problem / no caffeine drinks after tea time / provide a relaxing bedtime routine.

## How can I help prevent constipation?

- Allow privacy while toileting.
- Encourage the resident to drink more fluids.
- Encourage appropriate regular exercise to help movement of intestine.
- Encourage eating fibre in the diet e.g. five portions of fruit and vegetables a day.
- Record when the resident has their bowels open so you can check if it's been a while.

## How can I help prevent infection?

- Wash your hands after each interaction with residents; this is especially important with those who have an infection.
- Make sure injections are up to date – e.g. flu jab (residents and staff).
- Follow infection control procedures.
- Minimise the use of urine catheters.

## How can I help prevent falls?

- Make sure residents can see properly (glasses if needed, adequate lighting).
- Remove clutter so residents don't trip.
- Check that their shoes fit properly.
- Don't give too much sedating medication.
- Make sure you do regular checks on residents known to get up often in the night.

# Resources: Delirium

- [www.europeandeliriumassociation.com](http://www.europeandeliriumassociation.com)
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- Siddiqi, N. & House, A. (2006).  
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# WHAT IS Dementia?



**Dementia** is a disease of the brain, usually affecting memory, thinking, orientation (knowing what day/time it is, where you are), understanding, learning, capacity to make decisions, language and judgement. It is often associated with problems with emotional control, social behaviour and motivation.

## Causes

There are many causes of dementia. Alzheimer's disease, vascular brain disease and dementia with Lewy Bodies are the most common. While most follow a similar pattern, it is important to recognise that no two people with dementia are the same or have the same needs.

## How common is dementia?

**Under 65:**  
1 person in 1,000

**Age 65 – 70:**  
1 person in 50

**Age 70 – 80:**  
1 person in 20

**Over age 80:**  
1 person in 5

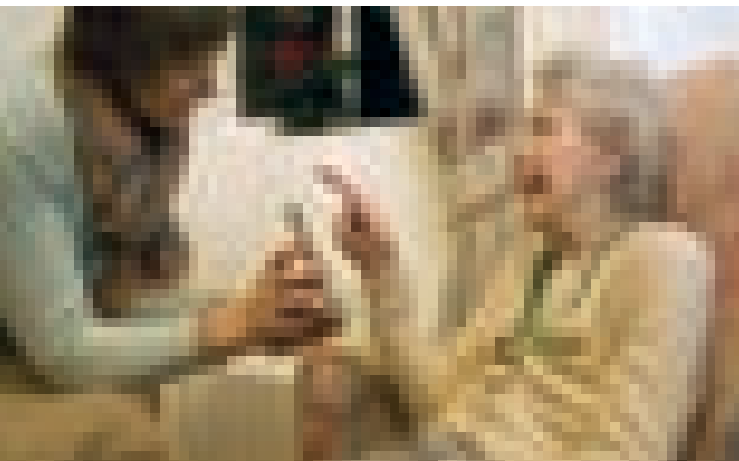
## Why is recognising the issues of dementia important for the care home environment?

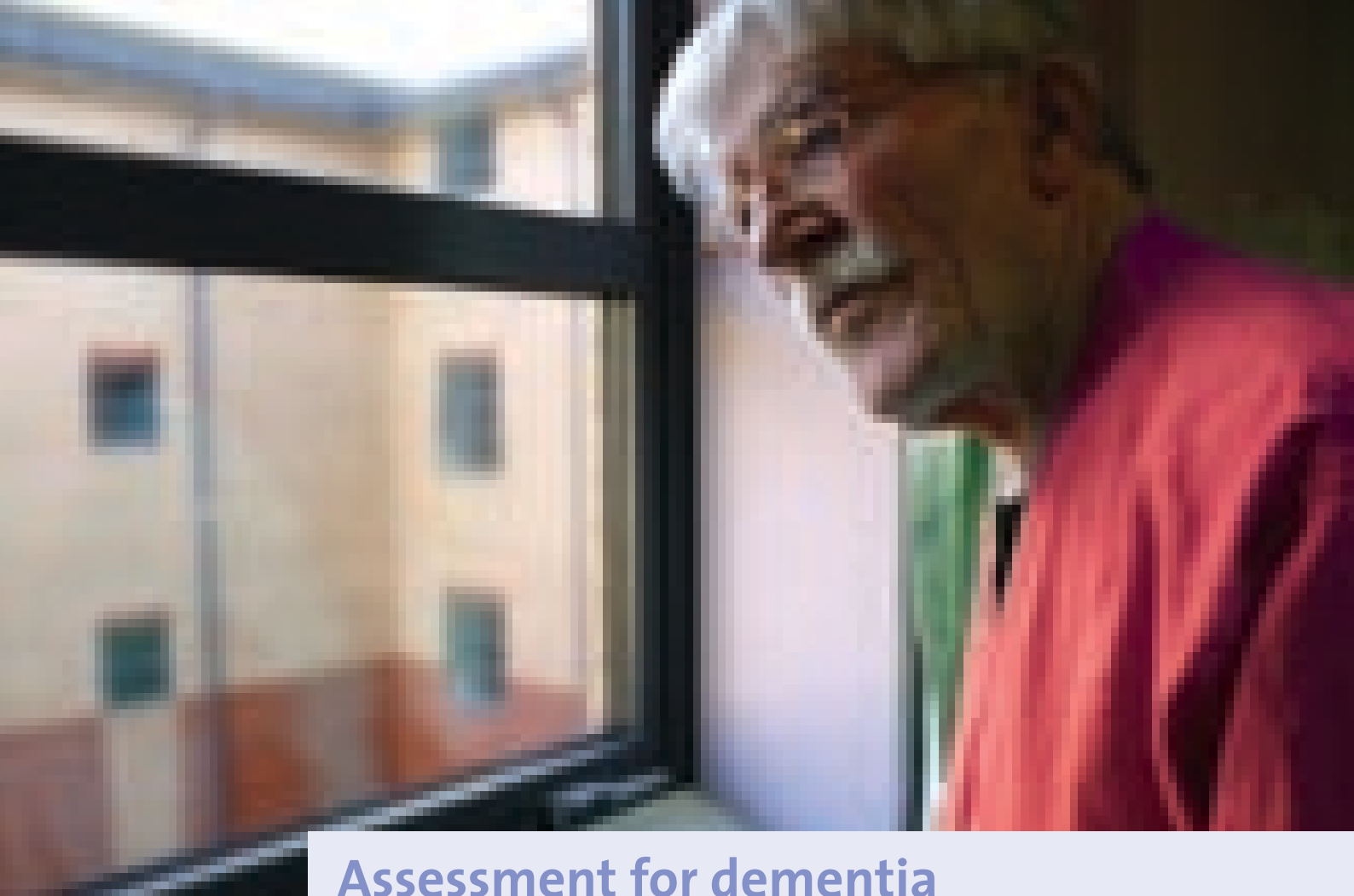
It is important to realise that admission into a care home can be confusing and disabling. People with dementia have problems in processing, understanding and responding to a strange environment and people and can therefore become more confused.

## What are the signs and symptoms of dementia?

Some or all of the following signs and symptoms may be present:

- short-term memory loss
- disorientation
- loss of problem-solving and sequencing skills
- loss of independence
- loss of ability to care for own personal hygiene
- loss of control over bodily functions
- not recognising things for what they really are (misinterpretation).





## Assessment for dementia

Dementia is usually diagnosed by the history of the illness, findings from a mental state examination and assessment, and the results of a physical examination. Once the diagnosis of dementia is established, the following things need to be considered:

- involving the person, their family, friends and carers (Life Story work).
- people with dementia are usually capable of expressing their needs and wishes through verbal or non-verbal communication.
- alongside this, their family, friends and carers should be involved to find out additional information to help plan their support and care.  
This is a crucial part of Life Story work.
- you can't know everything about every resident that you care for but learning important facts about people with dementia can certainly improve the way you care for them.

*(How to help someone using Life Story work is explored earlier in the folder.)*

## Person-centred care

In order to provide the best care to people with dementia in care homes it is important to bear in mind that the person has this diagnosis and this should influence the care and support that is provided to them. They should be at the centre of the care plan.

For example, it might be necessary to consider the level of capacity the person has to make decisions about a variety of issues, from what food to eat, what clothes to wear and their future care arrangements. The Mental Capacity Act (2005) stresses that all adults should be considered to have capacity unless proven otherwise. (This is further explained in a later section.) It is very important to encourage and enable people to make as many decisions about their everyday life as possible. This maintains their independence and helps them feel that they have some control over their lives. It is also respecting their dignity and gives them a sense of purpose.

If a resident has recently been admitted to your care home, their previous experiences may be reflected in the way in which they act with you.

If they are used to being busy all day about the house and to going out for a walk in the afternoon, this may explain why they are so keen to leave the home at a particular time every day or why they can't sleep at night. Learning about a person's relevant present and life history may answer some questions you may have about the way they act and you can plan their care and support around this information. For example, a resident who only eats 'finger food' may well do so because they no longer recognise cutlery. Try offering food that can be eaten by hand to improve daily intake, gently remind them what their knife and fork are for or seat them with other people who can still use cutlery – they may be able to 'copy' this behaviour.



- Considering how the environment impacts on the person with dementia may also help staff caring for people with dementia in care homes.
- People with dementia may be distressed by excessive noise, lighting, unfamiliar activity, the pace and number of people in the home and strangers.
- The person's memory, orientation and understanding may be affected by their dementia, leading to difficulties in understanding this often busy environment.
- It is therefore important to look at things that can be done to make life easier for the person. This might include the use of signage to orientate and direct the person and to make the home a safer environment. (This is explained further in another section of the folder.)
- Most important in all this is a thorough assessment of a person's physical and mental health needs, their history, their daily routines and their preferred methods of communication and interaction. A comprehensive and up-to-date care plan is essential to ensure all staff are aware of and can meet these needs. This is the essence of person-centred care.



# Language

The language we use and the way we talk about people can affect the ways in which we understand their behaviour. Sometimes we make assumptions when people behave in particular ways. Quite often it is difficult for people to express their needs and from time to time these needs can be expressed in behaviour that is easily labelled. Labelling a person's behaviour in particular ways can mean that their needs are difficult to see and understand.

In the following exercise a series of labels are listed against a set of needs that could explain a person's behaviour. When reading through the exercise think about the language you use. Have you ever used these words or phrases? What else might be going on? Have you ever had these feelings or behaved in this way? What good reasons did you have for feeling and behaving in this way?

*Derived from "Informed gender practice: mental health acute care that works for women" - NMDHU*

## Labels

## Better way of speaking

**"Aggressive" (kicking off)**

He sometimes behaves in ways that puts himself and others at risk.

**"Attention-seeking"**

She is trying to build relationships; she finds it hard to be alone with her thoughts and feelings.

**"Feeders"**

People who need support with eating.

**"Lazy"**

She cannot always remember; she may be in pain.

**"Likes their own way"**

She seems very unsafe and anxious. She feels better when her life is as predictable as possible.

**"Moaning"**

At the moment she is expressing some distress through her body.

**"Manipulative"**

He can feel insecure and sometimes attempts to influence others to try and regain control.

**"Paranoid"**

She experiences the world as very threatening and can feel unsafe.

**"Sneaky"**

He protects his privacy; he likes his own belongings.

**"Suspicious"**

She is not at the point of trusting us yet.

**"Unco-operative"**

She doesn't like what staff are doing to her.

**"Untreatable"**

We are finding it difficult to help her.

# Q&A Dementia

## How can I help with – **communication?**

- Reduce background noise and distractions.
- Slow your pace.
- Look for non-verbal signs to work out what the person may be feeling.
- Bear in mind that, due to their memory loss, the person may think they are meeting you for the first time.
- Do they respond positively to gentle touch – stroking the back of their hand, for example?
- If the person says one thing, do they mean another? Do they actually mean they want their mother or are they really wanting comfort and reassurance? What matters is not whether the statement is “true”; it is what the person thinks or feels at that time. This is what you should respond to.
- Validation is an appropriate response. You might say “You must miss your mum” and talk about the feelings. Respond to the feelings not the words.
- Do not correct or confront – it rarely helps and it makes people feel devalued.
- Do not worry about tears or laughter – go with the flow.
- Little and often. Do not use long, complicated sentences, and rephrase if necessary.

## How can I help with – **eating and drinking?**

- The person may not recognise knives and forks so may manage better with finger food.
- Offer familiar, appetising meals that can bring back memories (old-fashioned puddings etc).
- Do not automatically go to a soft diet if the person has problems chewing and swallowing. They need a specialist assessment and you need advice on the type of food they can eat. Good nutrition is vital for people with dementia.
- Have snacks and drinks available at all times – pieces of fruit, bread and butter, small cakes, juices and water, for example.
- Offer a variety of textures, colours and temperatures of food as this all adds to the person’s quality of life.

- Don’t ask people to choose their meal in advance. Offer choice at the time by showing them the meals available.
- If you have to assist with eating, respect the person’s dignity. Sit at the same level and go at their pace. Talk about the food and do not let others distract you from the task. Give them your full attention.

## How can I help people – **go to the toilet?**

- A person with dementia may not remember where the toilet is. Clear signage on toilet doors can help greatly, as can a different colour toilet seat. It can also be really helpful if the toilet doors are painted a different colour to all the other doors leading off a corridor, to make them more noticeable.
- Sometimes a person may seem to be incontinent, but actually their difficulties are caused by other health problems and disabilities. A urine infection, for example, can result in an urgent and frequent need to go to the toilet and the person cannot always manage to get there in time.
- People with dementia can experience difficulties recognising things and seeing the depth of an object. This can mean that, even though a person is able to see, they may be unable to recognise that a toilet is a toilet or make it out as separate from its surroundings.
- Going to the toilet is a very personal activity and it is important to treat the person with dignity and to respect their privacy as much as possible. They may not be able to explain that they need to go to the toilet and so it is important to understand and read their body language – for example, do they pull at their clothing or make a particular noise?

## How can I help with – **moving and handling?**

- Use clear communication about what is happening.
- Re-assure the person, hold their hand or distract them.
- Sing, smile or connect with the person through the task.
- Remain calm, risk assess and operate safely.

# Care needs at night

People who have dementia can become more disorientated at night – usually caused by a combination of mental / physical tiredness and lack of familiar daytime cues / activity. Learning about a person's usual day and night time routines may offer you information about their disorientation at night. It is worth considering that a worsening of a person's distress at night may also indicate the onset of delirium (have you got a night time care plan?).

## Stimulation, engagement and interaction

It is important that people with dementia are stimulated and engaged. Everyone needs to be able to interact with other people – understandably, people with dementia may get distressed or anxious or bored if they are expected to remain sitting in a chair all day.

- There are many opportunities to interact, even in busy routines – for example, during washing and dressing or meal times. These times can be used as opportunities to learn more about the person or simply to interact with them, using conversation, eye contact etc. Observing a person when providing care to them can also help with interpreting their behaviours and give them meaning.
- For example, a male resident may become distressed and verbally aggressive when being washed by a female carer. Perhaps this is because they are uncomfortable with being washed by a woman? Is there a male member of staff who could take over, and would this change the way the person is reacting?
- Interaction and engagement can also take place on a more therapeutic basis, not just when care is being provided. This might be through planned activities or on a one-to-one basis.

## Key points

- Get to know the person – interact directly with them as well as liaising with family / carers / friends.
- Find out about the person's communication needs and likes / dislikes / fears.
- Look for verbal and non-verbal cues from the person. Use short sentences. You may need to rephrase some questions.
- Explain who you are – you may have to do this every time you approach the person.
- Explain what you are going to do before you do it.
- Think about the environment – get advice from dementia experts – for example, the Alzheimer's Society.
- Interpret behaviour as communication – get to know the person in order to understand their actions and behaviours.
- Allow time in your interactions to enable a person with dementia to respond to you.
- If the person with dementia appears to have suffered an acute deterioration in mental state, consider the possibility of delirium. This is explored further in the section on delirium.
- Ensure the person is eating and drinking adequately. Don't assume that they will understand when food or drink is left for them. They may have forgotten how to feed themselves and if unsupported can become dehydrated.
- Assist and encourage people to use the toilet. A person with dementia may not recognise the toilet or the signage. They may not be able to verbalise or recognise their needs.
- Don't correct people – they may be experiencing a different reality and correcting their mistakes may cause distress.
- Provide achievable tasks that offer stimulation and can improve self-esteem.
- Always put the person at the centre of the care plan and ensure their dignity is respected.

# Things to remember

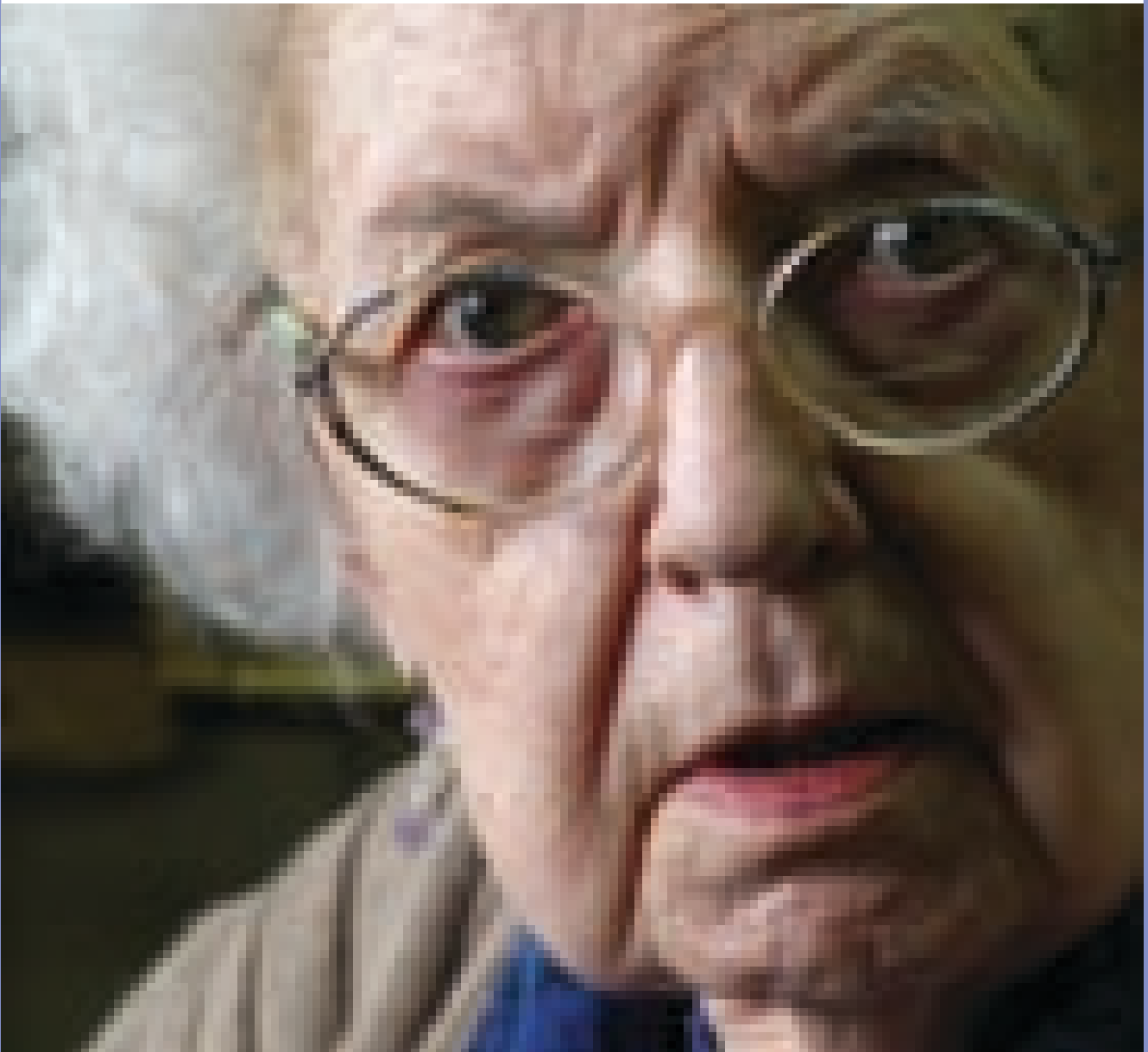
## about dementia



- Dementia is often not recognised in its mild form but can still cause difficulties for some people.
- You may think someone is being deliberately difficult but it could be a mild form of dementia; their understanding and reality may be different to yours.
- Dementia can be a really distressing experience, causing the person, their relatives and friends great anguish.
- The person with dementia can find it difficult to communicate and so staff can misinterpret signals – for instance, when someone is expressing pain.
- It's important that people with dementia remain as independent as possible by retaining their skills. Otherwise they quickly become dependent and may not be able to maintain skills. This will have a negative impact on their quality of life.
- Routine is really important when you have dementia. When you are in a care home your routine can be disrupted, which can be distressing and frightening. So consistency is important.
- It's possible that people can forget how to eat and whether they have eaten. Eating and drinking well has an impact on how people function.
- Care homes can be noisy, busy places and this can add to existing confusion and distress.
- People with dementia can sometimes be depressed too. They may appear withdrawn and sleepy.
- Someone with dementia can become agitated and this can impact on other residents, families, the care team and how the person is supported.
- Not everyone gets dementia but the risk increases with age.
- Poor care and treatment will make the symptoms worse and have a detrimental affect on the person's wellbeing.
- Depression and delirium can be experienced by people with dementia.
- You can include assessment and attention to dementia in the person's care plan.
- There is a lot you can do to help a person with dementia maintain a sense of wellbeing.

# Mrs Jones

## ...a person-centred approach



Mrs Jones suffers from vascular dementia and recently had another stroke. This has resulted in vision and co-ordination problems and loss of speech. When care staff approached her she was hostile. She spat and lashed out at them and did not want to co-operate when they tried to support her with her personal care needs.

She often made loud incoherent noises and would not let staff help her to eat, preferring to eat with her hands. Care staff were becoming reluctant to approach her because this would often result in them being nipped etc. They felt helpless and frustrated and were unclear about the best way to help Mrs Jones.

## The local Care Home Mental Health Liaison Team was asked to assess the situation.

### The team enabled the care staff to consider:

- **Communication** – how Mrs Jones's visual impairment, misidentification of objects, lack of co-ordination and lack of speech, as well as her long-term memory loss, were greatly affecting her ability to make her needs known, take medication and eat.
- **Assessment of pain or discomfort** – the Dementia Care Nurse observed that Mrs Jones was restless and agitated when she sat out in a chair and considered whether she was feeling uncomfortable or in pain, which may have been the cause of her shouting. When asked, Mrs Jones indicated that this was the case.
- **Loss of independence** – before her stroke Mrs Jones had been very independent, despite her memory problems. Care staff trying to help her eat, and take over her care could remind her of her loss of ability and independence.
- **Concentrating on what people can do rather than what they can't do** – it was clear that Mrs Jones felt happier feeding herself. Options that would help her independence, such as finger foods, toast, pizza, sandwiches etc, were explored with the care staff.
- **Staff attitudes** – staff attitudes were discussed to highlight how negative attitudes and language (although unintentional) could reinforce Mrs Jones's agitated behaviour.
- **Person-centred care planning** – a new care plan was devised that encouraged the care staff to spend more time with Mrs Jones rather than avoid her. They were encouraged to do this at times other than just when they were helping her with her personal care needs. This was to help develop a positive relationship and to gain her trust and confidence. Although difficult at first, with the support of the team and perseverance staff were able to develop a more positive and calm approach to Mrs Jones.
- **Inclusion in the life of the home** – Mrs Jones was seated in a different part of the home where she could see more activity and staff were more visible. This increased positive interaction and Mrs Jones became more relaxed and calm. She was, in time, able to have much better relationships with members of staff.



# Behaviour that challenges



A large proportion of care home residents with dementia are prescribed antipsychotic medication even though there is only modest evidence of its effectiveness.

There are also serious side effects such as increased mortality and heightened risk of falls, with all the consequences that brings.

**As a result an objective of the National Dementia Strategy is to reduce prescribing by two thirds over the next three years.**

The main reason for prescribing antipsychotics is to manage restlessness/agitation and to control behaviours that challenge others, also referred to as **behavioural and psychological symptoms of dementia [BPSD]**. However, these behavioural disturbances, such as wandering, aggression and shouting out are **unlikely to be symptoms of dementia and are more to do with a person's distress and frustration**. Possibly staff have inadequate knowledge of the person, their needs are not met, they are bored or communication is poor.

**Interventions should be psychosocial.** Getting to know the person better, ensuring their needs are met and their lives are still worth living will all help.

Antipsychotics should only be prescribed as a last resort when non-drug methods have been tried and failed. Only when distress is extreme or there is immediate risk to the person or others should

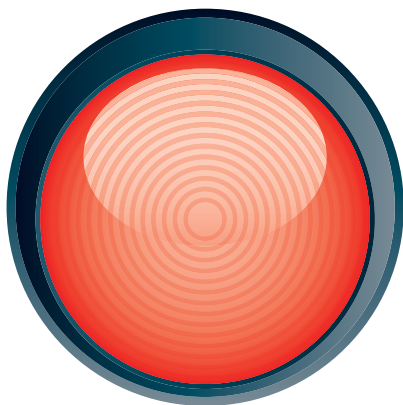
antipsychotics be used as an early intervention.

If antipsychotics are prescribed, treatment should be time-limited and regularly reviewed, at least every three months. Good practice guidelines recommend that antipsychotics should be stopped after the behaviours have been stopped or reduced to minimal levels for three months.

**Pain, fear, hunger and thirst, noise and over/under-stimulation are common causes of distressed and agitated behaviour.**

It is not surprising that unmet needs are thought to underlie behaviours that challenge. No matter how calm and person-centered you are, a person with dementia may still occasionally behave in a way that is difficult to understand or is perceived as challenging. Some behavior remains unpredictable.

**One approach that has been developed to help think about care plans and a person's needs is the “traffic light approach” (Sells & Shirley 2010)**



## Red

### CONTINGENCY

Risk management when proactive and reactive fail to meet needs. When an untoward event happens, the care plan should be acted on immediately to maintain the safety of others.

**Red for STOP**



## Amber

Reactive responsive – identifies and addresses changes in behaviour and levels of distress. This encourages staff to be vigilant to possible change in a person's mood.

**Amber for BE PREPARED**



## Green

### PROACTIVE

Preventative – meeting ongoing needs. This is the default setting. Staff should be attending to the person's wellbeing.

**Green for GO**

# Care Planning for Enid



Enid is an 88-year-old woman with dementia living in a care home. She has always been a quiet, unassuming woman who had a very small, close group of friends and who would avoid confrontation at all costs. She didn't like to bother people and didn't like a fuss but hated being treated unfairly. She rarely travelled out of her town but walked to the local shops every day. She nursed her mother through Alzheimer's and her husband through early onset dementia.

She uses a walking frame and wears glasses but they are often lost or broken. She has recently started to be incontinent of urine. She doesn't really know where she is and often thinks she is at a railway station, or at a school or work, and may try to leave the building. In the context of her dementia, she can get angry with staff when they try to prevent her leaving and with other residents, accusing them of not paying or being lazy. She has banged into them with her walking frame.

## Enid's needs

During a discussion about Enid's care, staff and the doctor identified Enid's needs as:

- to feel safe and secure
- to feel she has some control
- to feel she is being treated fairly
- to be occupied
- to have physical health appropriately managed.

# The team developed three care plans **GREEN, AMBER & RED**

## The proactive (green) care plan



- Make Enid's environment more familiar (paint door, decorate room like home) and personalise with similar objects to home.
- Spend a few minutes listening to Enid in order to establish where she thinks she is at any given time, and respond accordingly.
- Ensure Enid wears her glasses.
- Increase her fluids, monitor physical health, check MSU and bowels.
- Take her out every day for a short walk – contact local church for visitor.
- Let her open doors to see what is on the other side.
- Offer her choices about her daily routine and where to have her meals.
- Prompt her to go to the toilet before meals – for example, by saying "I'm a bit lost, can you help me to find the toilet?"
- Engage her help and give her constructive jobs, such as tidying, pairing socks, folding towels, clearing up after meals.
- Spend one-to-one time with her looking at books, photos and chatting about family.
- Engage her in small social groups for afternoon tea or coffee.

## The reactive (amber) care plan



- Monitor and manage environmental changes (noisy communal areas, meal times, slamming doors etc). Enable Enid to opt out at these times.
  - Monitor Enid for signs of distress or increased anxiety, such as walking more quickly, raising her voice, looking angry, muttering to herself.
  - Approach Enid in a calm, reassuring manner and acknowledge her distress. Listen carefully. If the source of the distress is external (for example, another resident) guide her away from the area. If it is less obvious then offer to help or talk about it.
  - Check if there is anything that she needs, such as to go to the toilet: "Is there anything I can get you?"; "Can I show you where all the facilities are?"
  - Offer to help her speak to the manager or person in charge to air her grievance. If no one is available, write it down for her.
  - Take her 'home' to her room or off the unit for a few minutes, either outside or upstairs.
  - Engage her in chat or ask for her help with a simple task.
  - Take her a cup of tea – make her feel special.
  - Monitor for any changes in distress levels.
- If there is a reduction in warning signs, then step down to green plan.
- If there is an increase in warning signs (shouting, stamping feet, banging walking frame, refusing to engage) then step up to red plan.

## The contingency (red) care plan



- Avoid any confrontation and try to remain completely passive. Only intervene if there is immediate risk to Enid or others. Guide other residents away from the area and guide Enid to her room or to a quieter area of the unit.
- Ensure her environment is safe. Discreetly remove risks.
- Allow her to wander round but provide constant observation from a distance. If she insists on leaving, let her go. Send someone new to meet her 'by chance'.
- A carer to approach her every 10 minutes but if she remains hostile then withdraw immediately. Use a different carer each time.
- Allow at least 20 minutes for her to calm down and forget the original upset before the level of supervision is reduced.
- When her distress subsides and she is able to engage, step down to amber plan.

# Older people with learning disabilities and dementia



Valuing People (the national strategy for learning disability) emphasises that people with learning disabilities

- have the same rights as everyone else
- have the right to choices about their life, like everyone else
- want to be supported to be as independent as possible
- want to be included in their community.

These apply equally to older people with learning disabilities and dementia.

## What is a learning disability?

It is known as “Intellectual Disability”. “This means that people will have difficulties understanding, learning and remembering new things ... and may have difficulties with a number of social tasks – for example communication, self-care, awareness of health

and safety.” Factsheet, British Institute for Learning Disabilities, 2004.

People with a learning disability are people first and we need to value their individuality. Like the rest of us, they dislike being labelled and always described in terms of their disability. So think about what people can do, not what they can't do and how you can support them.

## What do we know?

- There are approximately 25,000 older people with a learning disability.
- There will be a 36% increase in the number of older people with a learning disability by 2012.
- People with Down's syndrome have a much higher risk of developing dementia. The onset age is 30 to 40 years.
- At least 55% of people with Down's syndrome will be affected by dementia aged 60-69 (compared to 5% for the rest of the population) so this is a real issue for all of us.

## The early stages of dementia

The early stages of dementia in a person with learning disabilities are usually indicated by a loss of memory, and not being able to learn anything new. Recent memories may also be lost. The person may be disorientated at times and they might have more difficulty in communicating and understanding new things that are happening to them. There may be emotional changes, a loss of motivation and changes in social behaviour. Their sleep pattern may be disturbed. It is also important to be alert to other symptoms like depression.

# Good practice

## How can you support an older person with learning disabilities and dementia?

**Dementia is a condition that people usually get later in life. People with learning disabilities will already have some degree of cognitive impairment. It is really important to have an understanding of their abilities, strengths and skills in order to assess any decline that may indicate dementia.**

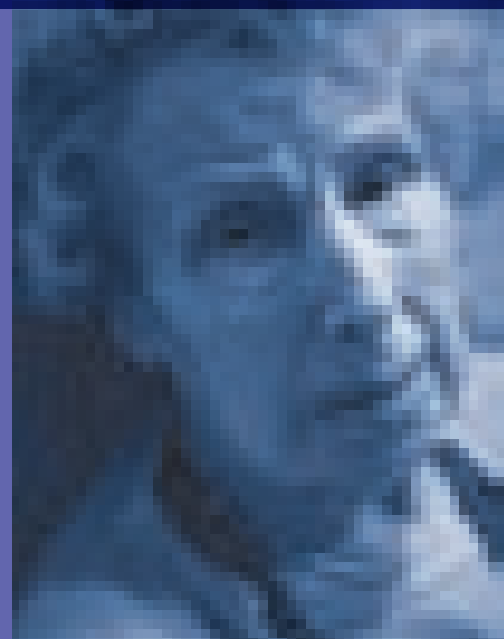
- Listen to what the person is telling you.
- Explain to the person what is happening if their circumstances are changing. Keep verbal requests clear and simple.
- Explain properly to them when you are helping them.
- Provide any written information in easy to read formats like pictures, symbols, photos etc. (Your local Learning Disability team may be able to help.)
- Remember that the person may need quiet spaces – crowds, and a busy environment may upset them.
- Remember that the person will still have skills and interests that should be encouraged. Make sure they keep in contact with family and friends.
- Involve them in decisions and use a person-centred and relationship-centred approach. This includes their likes and dislikes, how they prefer to be helped and what works and does not work for them.
- It might be helpful to work with local mental health, social care and learning disability teams to 'get it right' for the person.
- Remember that the age of onset of dementia for people with Down's syndrome is often younger than the rest of the population and therefore it is important to ensure environments and activities are age-appropriate. Younger people often have different tastes in music, activities and how they like their environment to be decorated and furnished.

## Additional health needs

People with learning disabilities have poorer health and receive less support from the NHS for a range of health issues, including cancer, heart disease and mental health. People with learning disabilities have an increased risk of early death compared with the general population. They are also more likely to have a visual impairment: people with Down's syndrome are at a high risk of vision and hearing loss. They are also less likely to be properly assessed and given the appropriate help.

People with learning disabilities are particularly prone to thyroid problems and depression. Without proper assessment, the symptoms of these can be easily assumed to be associated with dementia and may be left untreated.

People with learning disabilities are more likely to be either underweight or overweight.





## The ten absolutes of caregiving for Dementia

- 1 Never argue; instead, agree
- 2 Never reason; instead, divert
- 3 Never shame; instead, distract
- 4 Never lecture; instead, reassure
- 5 Never say remember; instead, say reminisce
- 6 Never say “I told you”; instead, repeat
- 7 Never say “You can’t”; instead, say “Do what you can”
- 8 Never command; instead, ask or model
- 9 Never condescend; instead, encourage and praise
- 10 Never force; instead, reinforce

# Delirium, Dementia & Depression

## Can you tell them apart?

Delirium can be difficult to tell apart from other common problems in older people – dementia and depression. It can be especially tricky if someone has delirium as well as having dementia, but this is very common. In fact, someone with dementia is five times more likely to develop delirium than someone without dementia.

The table below should give you some pointers for distinguishing between delirium, dementia and depression.

**REMEMBER, IF IN DOUBT, FIRST CHECK FOR A PHYSICAL CAUSE**

	DELIRIUM	DEMENTIA	DEPRESSION
Onset	Sudden (hours to days)	Usually gradual (over months)	Gradual (over weeks to months)
Alertness	Fluctuates – sleepy or agitated	Generally normal	Generally normal
Attention	Fluctuates – difficulty concentrating, easily distractable	Generally normal	May have difficulty concentrating, easily distractable
Sleep	Change in sleeping pattern (often more confused at night)	Can be disturbed – night time wandering and confusion possible	Early morning waking
Thinking	Disorganised – jumping from one idea to another	Problems with thinking and memory, may have problems finding right word	Slower, preoccupied with negative thoughts of hopelessness, helplessness or self depreciation
Perception	Illusions, delusions and hallucinations common	Generally normal	Generally normal

# Resources: Dementia

- Banerjee, S. (2009)  
*The use of antipsychotic medication for people with dementia: Time for action.* Department of health
- Cohen-Mansfield, J. (2000)  
*Theoretical framework for behavioural problems on dementia*  
*Alzheimer's care Today.* 1 (4)
- James, I.A. Stephenson, M. (2007)  
*Behaviour that challenges us: the Newcastle support model* *Journal of Dementia Care.* 15(5) 19-22
- Kitwood, T. (1997)  
*Dementia Reconsidered: the person comes first.*  
Open University Press Buckingham
- May, D. Edwards, P. and Brooker, D. (2009)  
*Enriched care planning for people with dementia.*  
Jessica Kingsley Publications London
- Shirley, L. (2008)  
*Developing new service provision for challenging behaviour in older people's care settings.*  
PSIGE: newsletter 105 28-53
- Stokes, G. (2000)  
*Challenging behaviour in dementia: A person centred approach.*  
Speechmark Editions, Milton Keynes
- **"Traffic light" approach** – More information can be found from:  
Debbie Sells at [Debbie.sells@ntwnhs.uk](mailto:Debbie.sells@ntwnhs.uk) or  
Louisa Shirley at [louisa@needsledcare.co.uk](mailto:louisa@needsledcare.co.uk)
- <http://ihsc.worc.ac.uk/dementia>
- <http://dementia.stir.ac.uk>
- <http://bradford.ac.uk/health/dementia>

# What is Depression?

We all feel sad from time to time. But when these thoughts won't go away we have to ask ourselves if this isn't something more serious, something called depression, that needs support or treatment. Depression is a treatable condition. We should never ignore it. The sooner we recognise depression, the more easily we can treat it.

Here are some of the symptoms of depression that you need to watch out for.

## Emotions

Some people may feel unhappy most of the time. They may feel hopeless and worthless, they may cry a lot for no apparent reason, they may be unable to enjoy themselves, they may feel anxious and may deny that they feel sad.

## Physical symptoms

There may be changes in their appetite. They may eat more or less than usual; they may experience weight loss/change, poor sleep and/or early waking, fatigue, weakness, constipation, aches and pains and headaches.

## Behaviour

They may become agitated. They may become demotivated. They may avoid people and activities and become dependent on care home staff. They may talk less and pay less attention to their appearance.

## Thinking

Their concentration may become poor. They may have difficulty remembering things, thinking and making decisions. They may dwell on things that happened in the past, or worry constantly. They may feel guilty.

# Depression

**Remember, no one person will experience depression in the same way. We all are unique. It is really important, therefore, that we get to know our residents well, so we can identify significant changes in their emotions, physical symptoms, behaviour, or thinking. We can get to know our residents better if we consult their family and friends.**

**This is why the Life Story work is so important.** *(See Life Story work section)*

In the most severe form of depression, (psychotic) the person may have delusions (these are false beliefs). They may believe, for example that they are wicked, need punishment for having done something terrible, or they may become frozen with fear that bad things will happen to them. Residents with psychotic depression may hear voices crying out negative comments about them – for example, that they are cheats and liars. They may smell bad smells undetectable by anyone else. They may become withdrawn and they may even stop talking or moving altogether.

## WHY IS TREATING DEPRESSION IMPORTANT?

Depression is not an inevitable part of growing old, but it is the most common mental health problem in later life, particularly among people with dementia. Treating their depression can help them live better with their dementia. One in two older people in residential care have symptoms of depression that are severe enough to warrant some form of treatment, but evidence shows that less than a third of them actually receive treatment.

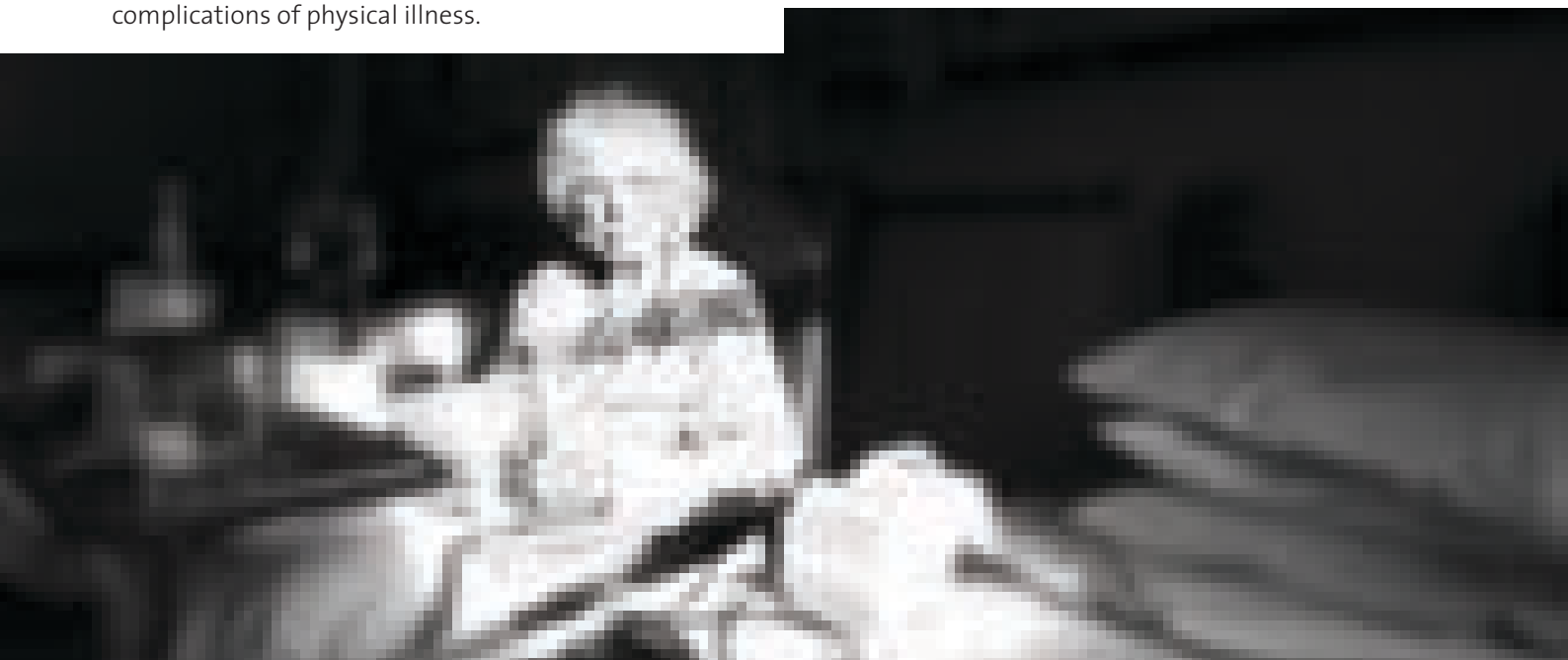
Depression is the leading risk factor for suicide among older people. Depression also increases the complications of physical illness.

- Only half of older people in care homes who are diagnosed with depression receive any kind of treatment.

If left untreated, depression can lead to residents:

- experiencing a lack of energy and motivation. They may become withdrawn, lose interest in the world around them, become apathetic and even soil themselves.
- neglecting their personal hygiene and appearance.
- having an increased risk of falls.
- not eating or drinking enough, which can lead to malnutrition and dehydration.
- not wanting to take medicines for other health problems.
- having thoughts about harming themselves or contemplating suicide.

Depression may be the cause of difficulties leading to the person's admission to a care home, as many of the symptoms of depression are of a physical kind, or may complicate treatment of a physical illness due to lack of motivation, poor compliance, poor appetite, weight loss and debility.



## WHAT CAUSES DEPRESSION?

People can become depressed for no obvious reason. Depression can be 'triggered' by a distressing life event, often connected with a loss of some kind, such as:

- Bereavement – whether the death of a loved one or another resident
- loss of good health, mobility and everyday functional abilities due to physical health problems
- Loss of familiar surroundings
- Loss of independence

In fact, research suggests that admission to care home itself can cause depression.

People can become depressed because they feel helpless, and cannot accept or adjust to changes in their lifestyle, as they review their life and dwell on the negative aspects of their past, or as they contemplate a future they see as bleak and hopeless. Consequently we need to be sensitive to a person's past, present and future when understanding the causes of depression.

## RISK FACTORS

Residents may be more at risk of depression if they:

- suffer from a serious health problem such as a stroke, heart attack or cancer
- have an illness or disability (like incontinence or Parkinson's disease) that affects the way they live
- have dementia
- suffer chronic pain due to arthritis, leg ulcers etc.
- lose their sight or hearing
- feel lonely or isolated
- have recently moved to a care home
- have recently been admitted from a general hospital
- have money worries
- use alcohol to excess
- take certain medicines (like steroids) that have "depressive" side effects.

## WHAT CAN WE DO ?

Prevention is easier than finding a cure. Here are some tips to help residents avoid becoming depressed. They should also help residents who may be experiencing mild to moderate depression.

### • Exercise

Exercise, however gentle, can help us all feel well and more positive. This is no different for care home residents. Exercise not only keeps us physically fit, it also helps us sleep. There is no reason why we cannot encourage most residents, even the most frail among them, to do daily stretching (and aerobic) exercises, take a walk, swim or learn yoga. These can be adapted to the needs of individual care home residents.

### • Healthy eating

We can help stave off depression by eating properly and not drinking too much alcohol. This applies just as much to care home residents as to any of us, and helps stop us becoming physically and mentally run down.

### • Staying social

We all need to get out and about. When residents stay in their rooms or isolate themselves from others, they can often brood over their problems. We can plan activities for residents that can be run by the care home staff or we can employ activity directors to set up group games, card games or organise outings to a concert or a play. If we cannot afford to hire activity directors, we can ask local voluntary groups to step in.

### • Alternative therapies

We can help alleviate some depressive symptoms with alternative therapies – although these need to be done by someone with proper training and experience:

- aromatherapy and massage
- meditation
- acupuncture.



## • Relaxation methods

It is important to reduce stress and anxiety amongst our residents by providing and encouraging them to do things that help them to relax. These could include:

- slow breathing exercises
- listening to calming music
- running a cookery or baking session
- joining in craft activities
- writing their life stories
- gardening

This list is not exhaustive.

Residents may already have hobbies, or other interests and enthusiasms. We should encourage these and/or get residents involved in new interests, like watching local football matches, or following the adventures of their favourite sports or film stars. Again, we can learn more about our residents by checking out their life stories.

The first thing is to be alert to depression as a possibility and take action.

Do not ignore its importance. Depression is not normal.

## HOW DO I SPOT IT?

Diagnosing depression in older people can be difficult, particularly in care home residents because the physical, behavioural and emotional symptoms could also arise from a physical illness. Symptoms typically include poor appetite, weight loss, weakness following a stroke and general worries about their health. There is also a general lack of awareness of depression among the general public and among professionals.

Older people also at risk of ageism: The attitude may be “What do you expect at your age?” There is also a stigma associated with mental illness. Older people themselves may be reluctant to ask for help or not know how. To recognise depression, it is important for us to recognise the psychological symptoms – the thinking and feeling patterns that characterise depression. Spotting depression among residents with dementia may be more difficult.

Involving families and friends is invaluable because they are usually best placed to recognise a change in the person’s usual ways of thinking and reacting to situations and have knowledge of their circumstances and mental state before admission to a care home.

## Look for clues

Knowing your residents through talking to them and an awareness of their usual behaviour can help you detect if something is wrong. Have you noticed that a resident in your care isn’t quite their usual self? Perhaps they are unhappy or just more anxious, irritable, moody or quieter than usual? If the resident is new to your care home, information from family and their friends is really important.

Remember, residents can hide their depression behind a smiling face.

Clues could be:

- taking little pleasure in visits from family and friends
- avoiding social activities
- a significant change in their usual routines
- beginning to neglect their appearance/personal hygiene
- moving more slowly than usual
- wringing their hands or pacing the room
- complaining that they are old and worthless
- changing their eating habits
- starting to refuse medication
- forgetting important occasions
- being ‘hypoactive’, withdrawn and inactive.



There are also several simple tools that can help with the diagnosis of depression. They can help to identify people most likely to be depressed by rating how well they perform in certain tests, but the tests do not make a complete diagnosis. After we come up with a positive test, we may need to make an appointment with the resident's GP but, before we do that, there are some screening tools that we can use.

The Geriatric Depression Scale can help us identify residents who are more likely to be suffering from clinical depression. It is designed particularly for use with older people and those with accompanying physical illness. Any staff member can administer this test, or residents can fill it out themselves in a few minutes by answering a set of questions that require a simple yes/no reply.

The Signs of Depression Scale (Hammond et al, 2000) may also be especially useful when the patient cannot communicate verbally.

These and similar instruments can aid diagnosis, but there is no substitute for spending time with a resident in private to discuss how they feel. Good, daily communication and knowing your residents well is very important.

Once we suspect depression in a resident, we should ask his/her GP to visit and make an assessment. It is important that you explain your concerns to the doctor.

Sometimes staff report that it is difficult to get a GP to attend. Sometimes GPs may think they are just being asked for prescriptions.

### Here are some TOP TIPS to help communicate with the GP

- Is the GP aware of the person's condition?
- Do they need to see a GP?
- Even if known, the situation may have changed and the resident may need a review. The GP can check that the person is not still taking medication that is no longer needed.
- Remember, even if a person comes in with a diagnosis of dementia or delirium they can still have depression.

#### DO NOT:

- just accept a prescription – talking and counselling /therapy works with people of any age.
- ask the GP to “give them something to calm down” – look at the person first, is it in their best interest?
- just accept antipsychotic medication for the treatment of depression.

#### DO:

- **describe any changes that you notice (the better you know your resident the easier this will be):**  
“Mrs Roberts normally wakes up at 6 and enjoys her toast. She has not been wanting to eat, she seems listless and did not respond when her daughter came to visit. This is not like her.”
- **describe what is worrying you.**
- **ask for a review to see what is needed.**

### The GP can then address:

- the person's mental state to gauge the severity of the depression
- risk of self-harm or neglect
- the impact this is having on their wellbeing
- implications for their physical care
- factors that might be contributing to the condition

Involving families and friends in the discussion is invaluable.

More detailed and personal discussions need to be conducted in private if the resident is to talk openly about how they are feeling.



If the depression is thought to be mild, particularly if related directly to their physical health and treatment, the GP can discuss the situation with the residents and give them support and reassurance. The GP may refer the patient for psychological treatment (see below).

## WHAT ARE THE PRINCIPLES OF TREATMENT?

We can treat depression in a variety of ways.

Two thirds of older people have mild depression that will often respond to listening, explanation, reassurance, encouragement and simple practical interventions. These require no specialist expertise or training and are usually best managed by the care home staff.

Moderate depression will usually require the addition of antidepressant medications, prescribed by the GP, or psychological treatments.

Severe and psychotic depression and any depression accompanied by self-harm or suicidal thoughts should be referred to the resident's GP, who is likely to refer them to the local mental health team as a matter of extreme urgency.

**Social** – Social factors, including loneliness and loss of independence, choice and respect, can be important factors in the development and persistence of depression in residents in care homes. Addressing these is an important part of treatment. Social activities, music, exercise and seeing family and friends may be helpful social interventions.

**Psychological** – Some degree of psychological intervention in the form of listening, supporting, encouraging and reassuring is of benefit to all people. More structured forms of psychological treatment (talking therapies) are appropriate for some people with depression but require training and specialist expertise.

**Physical** – People with moderate or severe depression may require antidepressant medications prescribed by a GP or specialist. Before administering such medications, they must consider a resident's prior history and current physical condition, then monitor the side effects of any given drug. The newer antidepressants are generally safe and effective in this situation, but the person's physical condition, risk of side effects, type of side effects and previous response to antidepressants, needs to be considered carefully when deciding which medication is right for them.

**Electroconvulsive therapy (ECT)** – In extreme circumstances, when everything else has been tried, the specialist may prescribe ECT for people suffering with life-threatening depression. The resident will have been referred to a specialist in old age psychiatry.

## RISK OF SUICIDE AND SELF-HARM

If we find that a resident has suicidal thoughts, we should refer him/her immediately to the GP or mental health team.

There is no evidence that talking about suicide increases the risk of it happening and our questions, far from planting the idea in their heads, can help residents give voice to their fears, and face them without guilt.

Our questions can be difficult to ask and can make us feel uncomfortable, but it is better for us (and for the residents) to ask them rather than avoid them.

A graded approach to questions is often easiest. For example:

“When you feel down have you ever thought life was not worth living?”

“Have there ever been times when you wished you were dead?”

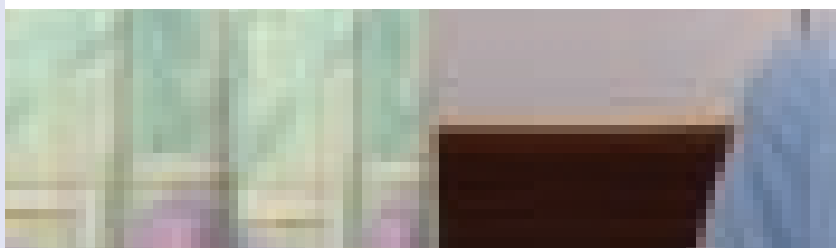
“Sometimes when people feel like this they think about ending their life. Have you ever thought like that?”

“What sort of thoughts like that have you had?”

## WHAT ASPECTS OF CARE NEED PARTICULAR ATTENTION FOR RESIDENTS IN CARE HOMES?

Preventing depression may require particular attention to the following:

- ensure that residents are eating and drinking adequately.
- prevent and pay attention to constipation.
- assist residents with their personal hygiene and care when there is lack of motivation or energy.
- gentle but persistent persuasion to engage the person in any tasks, with a consistent approach adopted by the whole team.
- give positive encouragement for even small progress or improvement. Avoid critical comments on failures – for example, don't say things like “You are wet again.”
- encourage achievable tasks to enhance residents' self esteem and avoid setting them up to fail – for example, leaving a resident to wash and dress themselves if they are unable to do so.
- encourage regular contact with family and friends, by telephone or skype if they are unable to visit.
- provide a level of stimulation and activity appropriate to the resident's abilities.



## ARE THERE POTENTIAL ISSUES TO CARE AT NIGHT?

Night time can be particularly difficult for depressed older people. Difficulty getting off to sleep, restlessness, nightmares or waking early are common. Night time and darkness is a lonely time and lack of distractions can lead to rumination over fears or feelings of hopelessness.

Attention to sleep hygiene may help some residents get a better quality sleep. The reassuring presence of a familiar member of staff who is willing to listen to worries and fears can be comforting. It may be easier for some people to talk about their thoughts in their own room or a quiet area. Or they may want music or to listen to radio as a distraction.

## HOW CAN I SUPPORT A RESIDENT WHO IS DEPRESSED?

- **Encourage a resident to get help.**

This sounds easy enough but it can be tricky as some residents may be reluctant to seek help or deny there is a problem. Asking their family or friends may be useful.

- **Learn about depression.**

Find out as much as you can about depression. For example, Age UK has lots of information for care home staff and for residents and their families as well (see references at the end). This helps us understand what we are dealing with and what to expect.

- **Build a good relationship with the person.**

Encourage residents to share their feelings and try to be a good and willing listener. Get to know residents and communicate with them on a daily basis.

- **Encourage activity and a healthy lifestyle.**

Exercise and healthy eating go a long way towards relieving depression.

- **Support their treatment.**

It can be weeks before the resident feels the benefits of treatment so we need to encourage them to follow through with their mental health worker or therapist appointments and/or to take their medication.

## WHAT SHOULD I REMEMBER ABOUT DEPRESSION?

- It is common among older people admitted to care homes.
- It is a serious condition that can be life-threatening.
- Untreated, it predicts a poor outcome for residents.
- Most people recover or benefit from treatment.
- If depression is treated, the outcome for the resident will be better.
- We can identify people at risk of developing depression when they are in the care home.
- We can include assessment and attention to depression in the care plan.
- We can prevent some cases of depression.
- There is a lot we can do to help residents recover from depression.
- We need to remember the risk of self-harm and self-neglect for residents who are depressed.
- Some depressed residents need specialist assessment from a GP or a specialist mental health team.

## QUESTIONS

- What can we do at work to find out if residents are depressed?
- What can we do at work to prevent and reduce depression among residents?



# Don't ignore Mrs Turner

**Mrs Turner is a 78-year-old lady who has been admitted to your care home. She is pale, diabetic and suffering from depression. She also wears a hearing aid.**

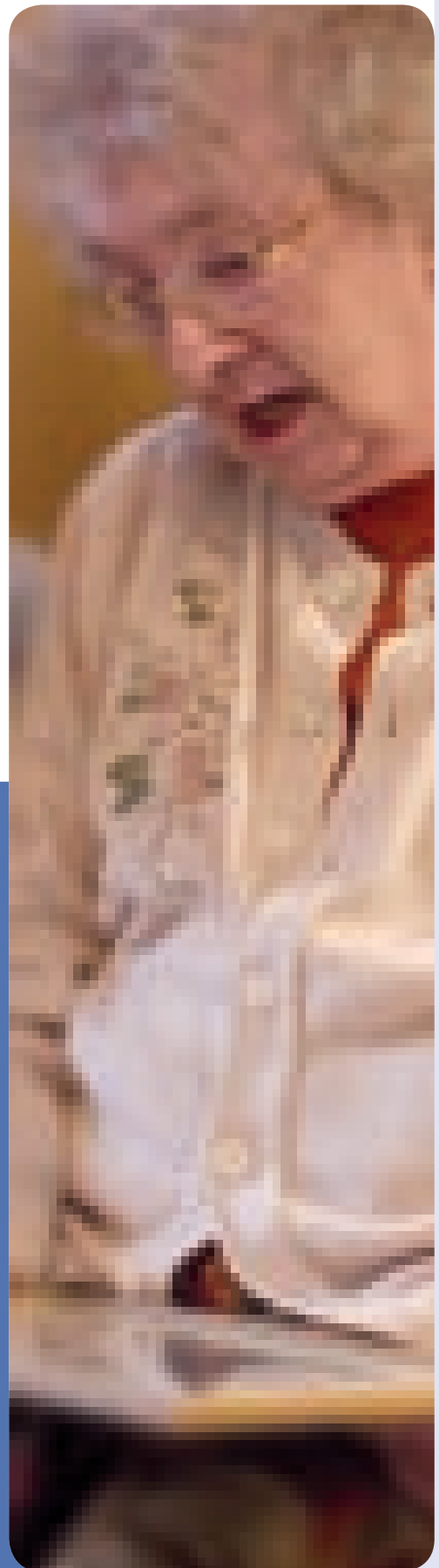
It is found that her diabetes is out of control and, after initial treatment and rehydration, her physical condition improves but her appetite remains poor. She is withdrawn and never starts conversations or approaches staff. She makes excuses to avoid activities and is not walking. She seems to lack interest in everything and you wonder if she is confused.

It is difficult to get her to talk while you are attending her in her room. She smiles but never asks for anything.

**You realise you know nothing about Mrs Turner herself. Her daughter has been visiting for 3 weeks but has never approached any of the staff. You record in her care plan the need to talk to her daughter in private to find out more.**

The daughter explains that her father died 9 months ago and her mother has been deteriorating slowly since then. She used to be a very independent and active woman who managed her own home and went to bingo twice weekly but this has all stopped. Her daughter suspects that she has not been taking her medication reliably for several weeks and in this time she has deteriorated more rapidly.

Her daughter tells you her mother is a very private person who does not talk easily about personal things and has not spoken about her husband's death. She is very self-conscious about her deafness and, without her hearing aid, misses conversation. She suffered depression 20 years ago after her mother died.



You talk to Mrs Turner privately, away from other residents. First, you discover the batteries in her hearing aid need replacing and arrange this. She confirms that she can now hear you better.

She tells you how much she misses her husband and that she was trying to cope without being a burden on her daughter. She was sure she was becoming “senile” because she could not concentrate and forgot things and was frightened. She knew she was deteriorating, losing interest in life and feeling hopeless about the situation. She could see no future and thought of taking her own life to be with her husband but could not find the energy to do anything. She was also worried that this would distress her daughter and so thought that if she stopped taking her tablets she would die naturally and this would not upset anyone.

You arrange to talk again and she is pleased. She says it has helped to be able to share some of the “bad” thoughts and feelings she has had. You look forward to hearing more from Mrs Turner. When you next talk to her, she tells you how guilty she felt since her husband died because he refused to go to the doctor when he was ill and she should have insisted. You suspect that she is depressed so you bring all this information to your manager who decides on a number of measures. Mrs Turner is referred to her GP because of suicide risk and possible need of specialist therapy.

Her care plan also pays particular attention to diet, involving the dietician and diabetic specialist nurse, plus things to improve her self-esteem including getting her hair done, taking every opportunity to praise her progress, taking a few minutes each day to talk to her, involving her daughter as much as possible and establishing a trusting relationship and making sure her hearing aid is always working.

## THEMES

- Recognise depression early and take action.
- Talk to people in private and in confidence when discussing personal things and feelings because conversations of this nature are seriously inhibited in open areas.
- Recognise how depression can affect a person’s recovery and rehabilitation.
- If depression is suspected, initiate a comprehensive assessment involving relatives/carers.
- Don’t be afraid to talk about sadness.
- If people are admitted to your home with depression, or taking treatment for depression, consider these possible consequences at the time of admission.
- Adopt a positive approach.
- If a patient has severe or psychotic depression or suicidal thoughts, refer them to a mental health team without delay.

**Mrs Turner finally improves enough to join in the activities. Without your initial suspicions and efforts, this might not have happened.**

# Delirium, Dementia & Depression

## Can you tell them apart?

Delirium can be difficult to tell apart from other common problems in older people – dementia and depression. It can be especially tricky if someone has delirium as well as having dementia, but this is very common. In fact, someone with dementia is five times more likely to develop delirium than someone without dementia.

The table below should give you some pointers for distinguishing between delirium, dementia and depression.

**REMEMBER, IF IN DOUBT, FIRST CHECK FOR A PHYSICAL CAUSE**

	DELIRIUM	DEMENTIA	DEPRESSION
Onset	Sudden (hours to days)	Usually gradual (over months)	Gradual (over weeks to months)
Alertness	Fluctuates – sleepy or agitated	Generally normal	Generally normal
Attention	Fluctuates – difficulty concentrating, easily distractable	Generally normal	May have difficulty concentrating, easily distractable
Sleep	Change in sleeping pattern (often more confused at night)	Can be disturbed – night time wandering and confusion possible	Early morning waking
Thinking	Disorganised – jumping from one idea to another	Problems with thinking and memory, may have problems finding right word	Slower, preoccupied with negative thoughts of hopelessness, helplessness or self depreciation
Perception	Illusions, delusions and hallucinations common	Generally normal	Generally normal

# Resources: Depression

- [www.nmhdu.org.uk](http://www.nmhdu.org.uk)
- Chew-Graham, C., Baldwin, R. and Burn, A. *The Integrated Management of Depression in the Elderly*. Cambridge University Press. Published April 2008. ISBN 978-0-521-68980-9.
- Hammond, M.F., O'Keeffe, S.T. and Barer, D.H. (2000) *Development and validation of a brief observer-rated screening scale for depression in elderly medical patients. Age and Ageing*. Nov 29(6) 511-515.
- 30 item '*Geriatric Depression Scale*' and the '*Signs of Depression Scale*' are available at:  
[www.bgs.org.uk/Publication%20Downloads/ABI-Appendix2b](http://www.bgs.org.uk/Publication%20Downloads/ABI-Appendix2b)
- AGE UK  
'*Depression ... it's more common than you think*' – patient and carer leaflet available at:  
[www.ageuk.org.uk](http://www.ageuk.org.uk)
- Royal College of Psychiatrists (2004) Assessment following self-harm in adults. Council Report CR122.  
<http://www.rcpsych.ac.uk/publications/collegereports/cr/cr122.aspx>
- Faculty of Old Age Psychology (British Psychology Society) has useful articles and ideas available at:  
[www.psige.org.uk](http://www.psige.org.uk)



# Quality of life

Consider my needs



This section focuses on quality of life, which can mean different things to different people due to their backgrounds. People from a variety of backgrounds will have different life experiences and not everyone's views and tastes will be the same.

In this section some broad themes are presented to provide ideas about some of the key areas that can be considered when thinking about a person's quality of life. While it has not been possible to list every theme in this folder, the ones presented are aimed at encouraging care teams to acknowledge this diversity.

# Activities



**Preparing vegetables** – to make vegetable soup. This does not have to be peeling potatoes; it can be scrubbing carrots, shelling peas, measuring out lentils, crumbling oxo cubes etc.

**A tea dance** – dining rooms should not just be for meal times. Move tables and chairs out into a circle, get tea and cakes, dance cards and music. A little enthusiasm goes a long way. Use themes: fish and chip supper, strawberries and cream teas etc.

**Brass cleaning** – brasso and cloths can keep people busy and provide a useful talking point about other cleaning activities, schedules etc.

Encouraging all residents to be involved in house chores if they choose to be, washing up, wiping tables, setting up for lunch, folding laundry, matching socks or cleaning shoes can all give a sense of purpose and occupation.

Cut out pictures of people, furniture, clothes etc from old catalogues, get PVA glue and card and let your residents loose to “create” families, collages, football crowds etc. This can be a talking point about fashion, ethnicity, family contacts etc.

**Baking** – it’s not scary, it’s not a health and safety risk, you can risk assess and allow older people the opportunity to create in the kitchen – or get a microwave that bakes and allow older people to create in the living room!!!! Making bread, for example, can be therapeutic as well as creative.

**Poetry** – can be emotive, but read with inflection, and enthusiasm it can create some laughs, some tears, and be an enjoyable afternoon.

**Industry** – if you have a factory or retail business that has been in your locality for a number of years, contact them for copies of old historical photos – see which of your residents remember people working there, or who may have worked there themselves etc. Create wall from old photos and packaging with the help of someone with artistic tendencies!

**Offices** – provide pens, paper, waste baskets etc – some people still enjoy writing and keeping records.

There is a wide range of activities you can do with your residents. You just need to think ‘outside the box’ and remember that not all activities will be suitable for all residents, especially if they have different physical and cognitive abilities. Do not become disheartened by this, but celebrate achieving small group involvements. Think activities through to ensure everyone has an opportunity to try something. This could be be tactile, for those with physical and cognitive impairment. Smell, taste touch can be just as stimulating as doing.

Check out the Alzheimer’s Society activity book at  
**[www.alzheimers.org.uk](http://www.alzheimers.org.uk)**

**Activities should be aimed at improving the lives of older people by providing real opportunities to improve physical, social and mental wellbeing.**



## **Why everyone needs daily, meaningful activity**

- Everyone needs to feel valued. For some people, moving into a care home can be an isolating experience, even though there are lots of people around. Good care involves making the individual feel included and valued, hence giving them a sense of wellbeing.
- We all need to feel a sense of identity – and this is an important factor when supporting people to choose meaningful activities. Use Daily Living Planners / Care Plans / life stories to make sure that people are maintaining their achievements in life as well as their physical and medical needs in their activity planning process.
- We all need to feel comfort, attachment and a sense of belonging – many activities will provide comfort to a person, especially those that involve social interaction with others.
- We all need to be occupied – there are lots of examples in our daily life of how people like to be purposefully occupied. Older people may lose the physical skills and capabilities to do things they used to do, but they may still be able to take part in some activities favourite and new. A useful tool here could be Life Story. Find out what the person used to do, at work as as a hobby or sport. This will give you some idea of what they enjoyed doing when younger. if you can find a way to match this with things they can do now, this could fulfil their need to be meaningfully occupied.
- We all need to have fun – whenever and wherever we find ourselves. We all need to have something that makes us smile to be able to smile in our daily routine – whatever that routine now is.



## Here are a few tips when thinking about activities!

- Use simple, achievable ideas.
- Remember that people with dementia are adults so don't ask them to do 'childlike' activities. For example, suggest they make bread, rather than making plasticine models.
- Meaningful and, more importantly, fun activities bring smiles all round!
- Activity doesn't have to be recreational – everyday tasks can be purposeful activity that promotes mental wellbeing and encourages social interaction.
- Use your own in-house staff / resources to include people in daily living activities such as making beds, washing up, setting tables, polishing, sweeping (imagine never being able to do this again in your life.)
- Involve the wider community – by making the most of local resources, organisations and events in and around your community.
- Focus on what your residents can do and what they want to do rather than what they are no longer able to do.

# Relaxation

## Know the person

**Find out as much as you can about how a person used to like to relax and use this information to help.**

## A warm bath

Some people find that soaking in a warm bath can work wonders when they are feeling stressed. The warm water relaxes them

physically, loosening tight, stiff muscles. And, as a result, they relax mentally as well.

## Spend time outdoors

Sunlight and fresh air have remarkable effects. Often something as simple as taking a short walk around the block can help. Walking together (whether it's inside or

outside), taking time to walk at the person's pace, listening to their angst and keeping them company can be enough to diffuse a tense situation or lift a low mood.

## Music

It's a proven fact that soothing music can be relaxing. Make sure it's the type of music that the person likes to relax to. Singing and laughter can bring on a smile. Happy singing, even nursery rhymes, can help people feel happier and more relaxed.

Music can connect people with their self and their emotions, and provide a connection with others and aid communication.

Music therapy uses singing to engage older people in an activity that promotes and maintains their quality of life.

Music can stir memories. Best results may be

obtained from playing music popular during the person's youth. People will respond best to their own favourites.

Singing along, swaying, or clapping hands with the music should be encouraged. Listening to music may awaken a desire to dance, which can be therapeutic.

A person's enjoyment is typically increased as they move or sing with music. Music can also be linked to other memory-stirring activities such as looking at photographs, and can provide some sense of shared feeling and emotion. It can also stimulate a sense of belonging and of who we are or once were.

## Hand massage

Hand massage works wonders. Doing a person's nails and massaging their hands using rich hand cream provides the opportunity to spend quality time with the

person, and also involves touch, which is known to be therapeutically beneficial. You do not have to be a trained masseuse to do hand massage.

## Time

**Giving your time and taking time to talk to and get to know someone is one of the best ways to make someone relax in your company.**

# Sleep

**Everyone has different ‘going to bed’ routines and different preferences about when and how they sleep. Getting to know someone’s routine can be very important.**

## Environmental Factors

Light and noise in the sleeping environment can be responsible for night time awakening. A sleeping environment that is too warm or too cold can also make sleeping difficult. An early morning truck, a streetlight outside the bedroom window, street noises and similar disturbances can make it hard to fall asleep and stay asleep. These external elements can be the easiest to identify, and the simplest to remedy.

## Physical Factors

Physical pain from arthritis and a host of other conditions that accompany the aging process can make it difficult to fall asleep and stay asleep. Dehydration, infections, over stimulation from television, caffeine from coffee or tea drunk late in the day – these are some typical culprits in sleep disturbance. Medications and drug interactions can also interfere with natural sleep cycles. Consult your GP if you suspect that medications might be contributing to a sleep problem.

## Sleep Disorders

Sleep disorders and disturbances come with a variety of characteristics and have many causes. Some of the sleep disorders that are common in people with Alzheimer’s disease include:

- increased frequency and duration of night time awakening
- daytime napping
- decrease in the time spent in deep sleep. This can lead to increase in awakenings
- difficulty falling asleep and insomnia
- sun downing – disorientation and confusion that often occurs in people with dementia late in the day
- shifts in sleep/wake cycle – more time awake during the night and asleep in the day.

# Tips to Improve Sleep

- Keep a bedtime routine.
- Make the bedroom and bed comfortable. It should be as the resident wants it and is used to.
- Try to avoid daytime naps.
- Television, visitors (especially children) and new and unfamiliar activities, can all unduly excite a person with dementia. Try to keep these to earlier in the day.
- A light snack before bedtime can improve sleep.
- If possible, encourage some regular exercise, but not too late in the day, as that can stimulate and raise body temperature, making falling asleep more difficult.
- Get some light every day. This is especially important in the winter when natural light levels are lower, and we're inside more. A walk in the sun or sitting in front of a sunny window can help regulate our natural biorhythms.
- Engage in a quiet, relaxing activity before bedtime, like listening to music, or practise relaxation techniques.

# A focus on pain

**“Living with pain”  
is a contradiction  
in terms.**

**Why?**

**If you are  
constantly in  
pain, you don’t  
have a life.”**

*Vanessa Wilson, 65*

**Pain is relatively common and we are all likely to experience it at one time or another.**

**But what happens when we are reliant on others for pain relief, and because of communication difficulties, we can’t tell anyone we are in pain?**

## Recognising Pain

Making assumptions about pain, is risky when a person may find it difficult to express their needs, is risky and can have serious consequences. Uncontrolled pain can dramatically affect a person’s quality of life. Because pain is so individual, pain cannot be ‘checked out’ by anyone else. Only the person feeling the pain can describe or define it.

## Introduction

Pain hurts. A person with dementia feels pain the same as anybody else. The big difference is that they may not be able to tell you in a way that you will understand. Never assume that someone is not in pain just because they don’t tell you.

People with communication difficulties may have difficulty in recognising and telling others that they are in pain. They will be relying on the ability of care staff and carers, recognise and understand their pain.

## What is pain?

- Pain can be defined as an unpleasant sensory and emotional experience associated with actual or potential tissue damage.
- Pain is a feeling triggered in the nervous system.
- Pain may be sharp or dull, it may come and go, or it may be constant, steady or throbbing, aching or pinching.
- Pain may be felt in one area, such as in the back, abdomen or chest, or may be felt all over, such as when the muscles ache from flu.
- Pain is usually referred to as acute or chronic, and these differ greatly:
  - Acute pain would be pain from a fracture, cut or burn.
  - Chronic pain would usually be associated with arthritis or other deteriorating conditions.

**MYTH** Pain in older people is highly prevalent and widely accepted as something to be expected and regarded as normal in later life.

## Pain is individual

- It’s what the person says “hurts.”
- It’s what the person describes and feels as pain.
- No other person can experience another’s pain, or know what it feels like, or how it affects the person physically or emotionally.
- It may cause discomfort, distress or agony.

### Don’t forget emotional pain

- This is as powerful and unpleasant as physical pain.
- It is caused by, among other things, by loss and social exclusion.
- Someone with dementia in a care home may be experiencing loss and social exclusion.
- They may be afraid or uncomfortable and be unable to recognise the feelings or tell anyone.

## Pain and behaviour

Sometimes behaviours that care staff find the most difficult to manage, such as rocking, repeatedly shouting and calling and hitting out, are all often dismissed as symptoms of the dementia, but they could also be signs of pain. While noise may be the most obvious indicator of distress, it does not always indicate that a person is in pain. Equally, someone who is silent and withdrawn may also be in great pain.

*Some care staff may believe incorrectly that people with dementia do not experience pain – or that, because their memory is so poor, they forget the experience.*

## The facts are...

- A person who has poor short-term memory may only be able to tell you if they are in pain **at that moment**.
- They may not remember if they had pain five minutes or five hours ago.
- **However, the physical impact of the pain remains.**

## Recognising pain is not an easy task

### Your skills

- Develop a way to communicate with each resident.
- Recognise that people may have difficulty with verbal communication.
- Recognise that people may be unable to communicate their emotions or feelings.
- Be aware of how your own behaviour can affect each resident.
- If you behave in a rushed, angry or agitated manner, residents can pick up on it and mirror your behaviour.

### Know your resident

- Use Life Story to help find out information that may explain a resident’s behaviours.
- Use information from carers, family and friends.
- Be aware of residents’ normal behaviour – this will allow staff to identify changes in behaviour and presentation.



## Observe your resident

Some common signs of pain are:

- increased agitation
- hitting out
- shouting, repetitive calling
- repetitive movements
- tense muscles; decreased ability to function at their usual level
- changes in sleep patterns
- increased pulse rate, sweating
- withdrawal
- not eating or drinking.

**Make a physical check –  
are there physical signs that could indicate pain?**

- Are the joints inflamed or swollen?
- Are there any pressure areas, sores, ulcers or broken skin?
- Is there a mouth infection?
- Are the resident's own teeth intact?
- Does the resident have a temperature, do they show difficulty in or have laboured breathing?
- Are they passing enough urine? Is the frequency or smell unusual?

Care staff should always ask the question:

**Are you in pain?  
Does it hurt?**

- Use your communication skills and your knowledge and understanding of the person to understand their response.
- Document your observations and concerns – this will help to provide continuity of care and vital information for the GP or qualified nurse.
- If you think the resident is in pain, ensure that they are clinically assessed by a qualified nurse or doctor.
- There are pain measurement tools that can be used by staff who are trained to use them.

**Never, never ignore symptoms of pain – this is a vital carer's role. You may be the only link between uncontrolled pain and pain relief.**

## Pain Check List

**Vocalisation** – *whimpering, groaning*

**Facial expression** – *looking tense, afraid*

**Changes in body language** – *fidgeting, rocking*

**Changes in behaviour** – *increased confusion, aggression, not eating*

**Psychological changes** – *temperature, looking flushed*

**Physical injury** – *recent fall*

# Margaret's story

Margaret became irritable and cross with care staff when she was being helped out of bed in the morning. Care staff were trying to get Margaret washed and dressed and while they were doing this Margaret shouted and screamed as they lifted her arms above her head to put on her jumper.

Afterwards she became very quiet and withdrawn and, as a result, didn't eat her breakfast or talk to anyone. Margaret seemed to come around about lunch time when she enjoyed her lunch and was her usual, happy self.

She was recently diagnosed with osteoarthritis in her upper body. This meant that, after sleeping, her joints stiffen and so raising her arms causes unbearable pain.



# Relationships



**Relationships are central to who we are. From the moment we are born, we are hard-wired to form relationships. This is essential for our survival.**

## **This handbook has talked about the importance of relationships throughout.**

The importance of relationships and someone to talk to (including family, friendships, and relationships with paid carers) is a basic human need and there is no reason to think that being in a care home or having dementia will change this. There is both a need for and benefit from human interaction for people in care homes. Physical health, the environment, and the ability or opportunity to engage in activities are also fairly universal needs.

### **Family and Friends**

**“Family, family is very, very, very special.”**

It is important, where possible, to maintain and encourage contact with family.

#### **Questions**

- What could you do to help the home be more welcoming to family and friends?
- Could there be a swing for grandchildren in the garden, or...
- Could you hold events that encourage family and friends to help organise and/or attend?

**“How another person reacts to you can make you very unhappy.”**

**“I feel lonely because I can’t speak English and I do not know how to communicate.”**

**“I have met people who are in very much the same boat as I am with things they can and can’t do... so for me it’s a relief, a bloody relief to find that there are other people in the same boat as me.”**

### **Sense of Humour**

**“Oh it is very important to have a laugh. ...Something that can make you laugh and being made to laugh is very important.”**

**“I strongly believe that humour with people...is important. If you can enjoy a joke or pleasantry with people, that’s a lift, you know, to me.”**

### **Importance of good two-way communication**

**“I think it would be nice if people gave the courtesy of time to finish what you are trying to say...so communicating I think it’s very important but [I] think it’s nice to give people the benefit.”**

(Quotations from: *My name is not dementia* (2010) Alzheimer’s Society and *Dementia - out of the shadows* (2008) Alzheimer’s Society)

# Personal Relationships

**Family and friends are important personal relationships. Often older people's sexuality and sexual needs are overlooked and it is often assumed that older people are heterosexual. This section of the folder encourages you to think about diversity and how people remain different and unique no matter how old they are.**

Sexuality is just one aspect of personal relationships. You don't have to be in a relationship to have sexuality.

"It's hard to get emotional closeness and great sex to come together in one relationship. I had an affair and enjoyed it but we didn't have any commitment as I did with my husband. It's true what books say: sexuality goes on all your life. But you can't split sexuality from emotion. To me, sexuality is intimacy."

(70-year-old woman)

Sexuality is a complex and multi-dimensional concept that describes:

- the desire for sex
- sexual activity
- sexual orientation
- values and beliefs
- a person's self-concept and self-esteem
- a sense of sensuality.

(Kaiser, 1996; Penhollow, Young and Denny 2009)

There is a common assumption that sexuality is only an issue for the young, and that older people have no sexual needs. However, sexuality is considered by many older people to be a life-long need and it has been shown to play an important role in their mental health and well being.

(Davies et al)



It is a subject that people find difficult to think or speak about. Care staff may worry that they will "open a can of worms." They may see sexuality as an important issue but "not my job." Certainly the expression of sexuality by people in care homes can be seen as problematic, and is seldom regarded as a positive aspect of a person's life.

**"I didn't think they would have sexual needs."**

**"I didn't even think they would think about it."**

**"On top of all our other worries, we have to think about that!"**

**"Older people weren't asked in surveys about their sexual activity because everyone knew that they had none, and they were assumed to have none because nobody asked"**

(Alex Comfort, 1972)

## Questions

- Is sexuality an issue you include in your assessment of clients?
- What would you record in the sexuality section of the patient notes?
- Have you experienced any problems of a sexual nature from clients? If so, what?
- How comfortable/competent do you feel assessing issues of sexuality?
- Have you received any training in this area?
- Are you aware of any guidelines in this area?

# Relationships



**“Because she had been married and had three children, it never even occurred to me that she might have had a relationship with another woman.”** *Care assistant*

**“Rosaria would like to go out to a local gay pub with three of her closest female friends on a monthly basis.”**

**“When I visited Jean in the home, she was always sitting in the main lounge with other residents. This made it more awkward for me to hold her hand or give her a cuddle. I didn’t feel confident enough to ask the staff to move her to her own room so that we could be a lone for a while. I felt like I was in a goldfish bowl with all eyes and ears on us.”** *Hannah*

**“We don’t have any gay people so it isn’t an issue.”**  
**Out of 50 people in a care home three residents could be gay.**

**If it is hard for people to think about heterosexuality and older people, the needs of older gay and lesbian people are often even more hidden. For many of the current generation of older people, homosexuality, would have been illegal when they were younger and there still may be stigma in discussing it.**

It has been estimated that 6% of people are gay or lesbian. This means some 49,200 gay people in the UK are living with dementia in Great Britain. Three in every 50 people living in care homes could be gay.

This could result in them feeling isolated and frightened about ‘coming out’ as there may not be a gay community where they feel safe in expressing themselves. Coming out can be a worrying and scary experience as sometimes people can be unreceptive towards gay people.

According to the gay campaign organisation Stonewall, older people face several issues that affect the provision of social services in the UK. Currently, gay people are more likely to live alone when they are older and are more likely to be without children. Gay people sometimes have different social networks, such as friends who are often regarded as extended family. Gay people also socialise with other gay people in gay venues that straight people don’t frequent very often.

## See Me

- Disclosure of sexual orientation can be difficult and may make me upset.
- Lack of immediate family support could make me feel lonely.
- Increased senses of loneliness and a lack of understanding of needs could make me frustrated and upset.
- Because I have non-traditional next of kin, I may feel awkward, embarrassed and scared that you won’t like me.
- A lack of understanding might mean that I lose my appetite and become depressed, or exhibit behaviour that you find challenging.

## Care workers

- Care home workers need to make it easy for residents to come out as gay.
- Care workers need to recognise the importance “families” in the gay community.
- Care homes, wards and day centres need to be culturally aware of how to support same-sex partners.
- Care workers need to feel comfortable spending time socially in a gay venue.
- Family members and friends need to feel welcome, consulted and an active part of their loved one’s care plan.

**“My partner and I had been together for 25 years when he was diagnosed with Alzheimer’s...When he went into hospital I kept on telling them that I was his partner, but they moved him into residential care without asking me. I phoned up to see how he was and he wasn’t there.”**

**“George would like to have his subscription to Gay Times continued. He enjoys having some of the articles read out to him. He likes going through the ‘personal ads’ column thinking about who he might like to contact.”**

**“Sometimes we assume that all older people are straight but we need to remember that they may be gay. If people are gay then this will have an impact on effective delivery of care and support. A thorough needs assessment is necessary to generate a care plan that recognises the needs of older gay people.”**

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- ***Issues facing Older Lesbians, Gay Men and Bisexuals***. Age Concern (2002).
- ***Opening doors to the needs of older lesbians, gay men and bisexuals***. Age Concern England (2002).
- E. Brown (2002). ***Lesbian and Gay issues in Residential Care Homes***. (Blackpool, Fylde, Preston & Wyre).
- L. Cook-Daniels (2002). ***Lesbian, Gay Male, Bisexual and Transgendered Elders: Elder Abuse and Neglect Issues***.
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- P. Gagliesi (2002) ***Efficacy of group psychotherapy for homosexual aging males***.
- Heaphy, A., Yip, D. Thompson (2003) ***Lesbian, Gay and Bisexual Lives over 50***.
- ***Triple jeopardy: Targeting older men of color who have sex with men***. A. Jimenez (2003).
- G Kitchen (2003) ***Social Care Needs Of Older Gay Men and Lesbians On Merseyside***.
- J Lockhart (2002) ***The Gay Man’s Guide to Growing Older***.
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# Spirituality, Religion and Belief

## Spirituality

If we believe in God, spirituality means one thing. If we do not believe in God, it means another. Either way, however, our 'spirituality' compels us to ask ourselves about the meaning and purpose of life. Spirituality is a more all-embracing concept than religion. One metaphor describes spirituality as a journey with religions as different modes of transport.



## What does spirituality do for us?

Spirituality can help individuals “look on the bright side of life.” With that sense of optimism – seeing the cup as “half full rather than half empty” – we can develop a sense of our own worth and value and that can give us inner strength and peace.

Spirituality may be viewed as an expression of an individual's essential humanity, of how we live our lives and deal with the crises that threaten to drown us. For staff using a whole-person approach, it is an essential element in the assessment, support and recovery of those they want to help.

You don't have to be religious to have a sense of spirituality. You may want to think about the following:

**What gives you meaning to your day?**

**What do you enjoy doing?**

**How would you feel if you could not do it?**

## Religion

All religions provide a world view, often acted out in stories, teachings, symbols, rites, rituals, sacraments and gatherings of the like-minded in communities that have a sense of mutual obligation. Religion creates a framework where people can make sense of their lives and their daily experiences. Religion can help people, but can sometimes be a source of distress. It is helpful for staff to talk to their residents, to find out what it is about their religion that may help or, on the other hand, disturb them. Some religions are quite culture-bound, so it helps if staff can make themselves aware of some simple taboos.

There are some beliefs and practices that will be particular to specific faith communities but the precise interpretation and patterns of adherence may be different for each individual. Here is a brief list to get you thinking.

Devout Muslims may not drink alcohol, but a resident who says they are Muslim may still drink - whether openly or covertly.

Some people from particular religions (e.g. Sikhism) may regard having a bath as grossly unpleasant and will wish to shower instead. This may also be the case for Muslims.

An individual who is Rastafarian or Jewish may refuse to eat pork and would find it distressing to have to eat it. Again, assumptions cannot be made but the possibility needs to be considered. Sikhs do not eat Halal food.

Religion will affect how people wash (even their hands), the way they wipe or clean the kitchen, how they display love and affection, what they read, watch or listen to and how they use their time (eg. some people will read scriptures at particular times of the day)

For example, Islam plays a significant role in satisfying physical as well as spiritual needs. Islam teaches a code of behaviour, conservation of social values, and gives a meaning to life. It helps in toleration and developing adaptive capacities for stressful events of life. It gives a sense of self-respect and teaches about the virtues of family life and a cohesive society with a sense of brotherhood.

The most important thing to remember is that religious prohibitions or preferences may be so intergrated into the sense of self that any breach or deviation will feel like an emotional assault.

**“It is impossible to know all of the intricacies of specific religious and spiritual belief systems. What is more important is treating them seriously and humanely; and trying to understand and support the issues each individual faces and the challenges they are grappling with, especially when it comes to rituals around end of life care.”**

*Peter Gilbert - Project Lead for The National Spirituality and Mental Health Forum. Some of this work can be done as part of Life Story work and getting to know a person.*



**Mrs Malik is an 82-year-old woman. She is Muslim and is originally from Pakistan. She prays five times a day. Before praying she carries out a ritual washing (wudu). In Islamic faith, elderly people or ill people may perform prayers by sitting or lying facing Mecca (south east). Being an elderly person Mrs Malik performs her prayers sitting down. She cannot read Quran (the holy book of Islam) but she recites verses of Holy Quran and makes supplication.**

Mrs Malik likes to eat permissible (Halal) Asian food as Muslims are strictly guided from their childhood about forbidden (Haram) food. In Islam forbidden food is; anything from pig's meat or

## CASE STUDY

# Mrs Malik's story

fat because it is considered as an unclean animal, or the meat from an animal that has not been slaughtered in the name of God or the correct Muslim way. She does not like to eat food that is stored with forbidden (Haram) food, or cooked with the same utensils or oil.

She likes to eat curry and pilao rice with mango achar (pickles) and chatni (sauce).

Mrs Malik covers her head and feels comfortable in Asian dress. She doesn't like to wear a gown while she is in hospital. She is always fully dressed when she is in bed. She prefers to see female doctors and doesn't like unnecessary physical contact with male doctors. She never says the words "thank you" or "sorry" but it doesn't mean she is rude; she is just not used to saying those words.

The month of Ramadan (fasting) is very important for Mrs Malik. She likes to fast. The fast starts just before dawn and breaks at sunset. There is an obligation of fasting for all Muslims except those who have mental or physical health issues. Being an elderly person she has health issues, so she skips fasting if she is not well.

She likes to watch TV drama and news. She likes to watch Asian programmes on television.

*(With kind permission from Atifa Liaqat)*

# Not everyone is as observant as Mrs Malik – indeed Mrs Begum does not want staff to assume she will want to pray five times a day. But she does insist on Halal food.

## It is important not to make assumptions about a person's culture or beliefs.

We might wait for a person to talk to us about their beliefs, but we can start up a helpful discussion by prompting him/her with open questions.

You might start generally: **“We want to help your stay be as right and comfortable as possible. We know that many of us have private hopes and fears or ways of looking at the world. We’re used to all sorts of wishes and want you to be able to tell us what you need.”**

Then continue to ask about faith and belief in a gradual way. This may take time.

For example:

- **Do you have a faith tradition?**
- **What is your church or faith community?**
- **How important is faith to you?**
- **How do your religious and spiritual beliefs apply to your health?**
- **How might we address your spiritual needs?**
- **What helps you most when things are difficult, when times are hard?** (for example when facing big problems, major losses or important challenges?)

Practical ideas might include:

- **asking residents about their spiritual and religious needs throughout their care and treatment.**
- **helping residents to identify those aspects of life that provide them with meaning, hope, value and purpose.**
- **ensuring that all residents, including those who do not regard themselves as spiritual or religious are offered the opportunity to speak with a chaplain or other spiritual leader if desired.**
- **providing good access to relevant and appropriate religious and spiritual resources.**
- **offering or making available safe spaces where residents can pray, meditate, worship or practise their faith.**
- **providing opportunities for residents to discuss their spirituality or religion with others.**
- **building strong and effective links with religious and spiritual groups in the local community.**

## Sometimes we think we may upset or offend people by asking them about their religious beliefs but usually people are happy to talk about it.

Although it is acknowledged that religion can have negative effects, confidence is growing in the benefits to both physical and mental health of spiritual beliefs and practices. This confidence is based on substantial research: 20% of studies report negative effects, 80% identify spiritual/religious beliefs and practices as beneficial, not so much part of the problem as part of the remedy. (Koenig et al, 2001; Levin, 2001)

Spirituality “comes especially into focus in times of emotional stress, physical and mental illness, loss, bereavement and death.” (RCP), so you can see it is of vital importance within care settings. It is not ‘airy fairy’ but is about “practices” or things that can be done.

These might include:

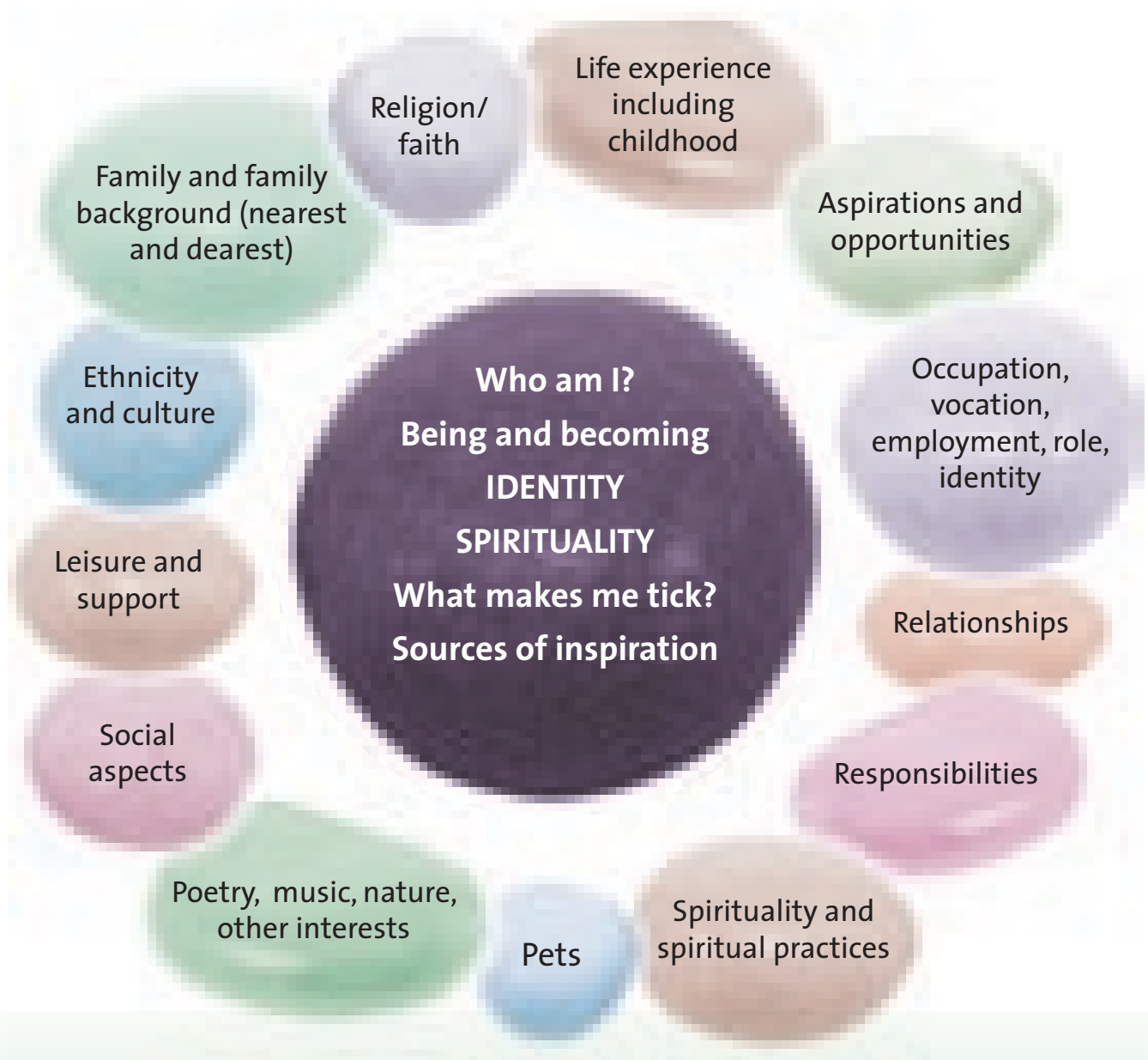
- **practices of the body**  
– relaxation, exercise, yoga, walking and singing
- **practices of the mind**  
– mediation, prayer,
- **religious practices**  
– from particular faith tradition.

As you can see from the spirituality and identity diagram opposite, this links to Life Story work and who a person is and what their hopes still are .

Sometimes staff do not feel confident to talk about spirituality, faith or religion. Some fear it will be seen as preaching, while others do not feel confident having these conversations. It is good to be aware of what feels right for you as a member of staff. If a resident does not seem to want to talk and you feel this is ‘not for me’, then maybe another member of staff feels more comfortable about it. You may have a chaplain or imam who visits and can provide support, or volunteers from a local faith community. It is important that residents feel they can have these conversations if they need to. It is also important not just to assume that “the chaplain can have that conversation.” However, you may already be doing a lot to address the spiritual needs of your residents. Sitting with them on a fine, sunny day or helping them to feed the birds may also be a spiritual experience for some people. Spirituality is not just for chaplains.

# Different approaches in mapping spirituality and identity

One way of 'mapping' spirituality and identity for yourself, or with others, may be as follows.



## Blocks to having these conversations

We have to acknowledge our own vulnerability.

- Empathising with people we see as being 'not the same as us' may pose challenges for us.
- Looking inwards into what makes us tick can be threatening and uncomfortable.
- It is easier to do the 'us' and 'them' bit.
- We may have to accept that we don't have all the answers.

## Support for staff

Spirituality and faith is an area that staff may find complex and stressful. It is important for the organisation as a whole to provide staff with:

- leadership, policy and operational guidance, supervision and
- a clear value base
- support, supervision and development
- an opportunity to explore their own spirituality, if they wish it
- specific training where required
- specialist chaplaincy back-up
- networking and visits, and
- opportunities to undertake project work.

“We are not human beings seeking to be spiritual. Rather we are spiritual beings striving to be human.”

(De Chardin)

## Resources

- Guidelines for staff on spirituality for staff in acute care sector setting. NIMHE, 2003. Available from: Peter Gilbert at [pgilbert@gilbert88.fsbusiness.co.uk](mailto:pgilbert@gilbert88.fsbusiness.co.uk)
- Staffordshire University (Centre for Spirituality) [www.staffs.ac.uk](http://www.staffs.ac.uk)
- Mental Health Foundation websites [www.mhf.org.uk](http://www.mhf.org.uk)
- [www.spiritualcompetency.com](http://www.spiritualcompetency.com)
- [www.mindandsoul.info](http://www.mindandsoul.info)
- [www.telos.training](http://www.telos.training): Specialises in providing training on meeting spiritual needs of older people with dementia in residential and community settings.
- [www.levenson.org.uk](http://www.levenson.org.uk) was formed in 2001. It brings together for study, reflection and exchange of ideas those of every faith and none.
- Christian Council on Ageing. The CCOA acts as a Christian voice and action on issues that matter to older people in Church and Society. It encourages Churches to make provision for appropriate pastoral care, affirming fellowship, meaningful worship, and relevant ministry for their older members. The CCOA also publishes a range of helpful books and resources on spiritual care and older people. [www.ccoa.org.uk](http://www.ccoa.org.uk) Telephone: 0845 094 4161

### DVD's

- “It's still ME Lord” is a film exploring spirituality and dementia. It can be obtained from: Caritas Social Action Network [www.csan.org.uk](http://www.csan.org.uk) tel 0207 901-4875
- “Spirituality – have you found any yet?” A DVD produced by Alzheimer Scotland and Faith in Older People to help staff and people living in care homes realise spiritual needs. See [www.faithinolderpeople.org.uk](http://www.faithinolderpeople.org.uk)

### Books

- Brooker, Dawn. *Person centered dementia care – making services better*. Jessica Kingsley Publishers, London, 2007
- Mary Ellen Coyte, Peter Gilbert and Vicky Nicholls. *Spirituality, Values and Mental Health : Jewels for the Journey*. Jessica Kingsley Publishers 2007
- Goldsmith, Malcolm. *In a strange land – People with Dementia and the Local Church*. 4M Publications, Southwell, Nottinghamshire (2004)
- Hammond, G and Moffitt, L. *Spiritual Care – Guidelines for Care Plans* (available from the Christian Council on Ageing – see above)
- Mackinlay, Elizabeth. *Ageing and Spirituality across Faiths and Cultures*. Jessica Kingsley Publishers (2010).

# Capacity and decision making

Consider my needs



Support people to make their  
own decisions wherever possible

# Managing Risk Safely

**Keeping people safe in care homes can be one of the biggest barriers to providing person-centred care, as is understanding how this connects to managing risk. Organisations often find it difficult to help people to have more control over their lives and can have an overly cautious attitude to risk, particularly with residents with dementia or a learning disability.**

Risk management starts with understanding what is important to the person – for example, their wellbeing and their need for love, comfort and social inclusion.

It is important to develop a culture within a care home that recognises the strengths that each person has and builds on what a person CAN do as opposed to focusing on their disabilities. This is what is known as “risk enablement”.

**Not everyone is at risk, not everyone with dementia is at equal risk – it depends on the person.**

Running alongside risk enablement is the legislation – ‘The Mental Capacity Act 2005 (MCA)’ including the ‘Deprivation of Liberty Safeguards (DoLS).’ These are the legal part of enablement that underpins all the care we give. It is about a whole-life, whole-person approach, linked to the end of life care and to dignity. It is important that legal issues are integrated into our everyday work and not regarded as JUST legislation.



# My rights, care, treatment and decision-making

Older people with conditions such as dementia or serious mental health problems are subject to the same legal safeguards governing their care, treatment and decision-making in general that apply to other adults. The two main pieces of legislation are the:

- **Mental Capacity Act 2005** (and Deprivation of Liberty Safeguards)
- **Mental Health Act 2007**

## Mental Capacity Act 2005

Mental capacity – or the ability to make decisions – is an issue that affects everyone. We all make decisions, big and small, of our lives. Most of us are able to make these decisions for ourselves, although we may seek information, advice or support for more serious or complex decisions. However, illness, injury or disability, may have affected some people's mental capacity. This can prevent them from making certain decisions about their lives. This may be temporary or permanent, and therefore decisions may need to be made on their behalf.

### A lack of mental capacity could be due to:

- a stroke or brain injury
- a mental health problem
- dementia
- a learning disability
- delirium
- confusion, drowsiness or unconsciousness
- illness or treatment of an illness
- substance misuse.

The Mental Capacity Act was introduced to create a proper legal framework to support people to make their own decisions wherever possible but also to create legal processes and safeguards when decisions have to be made on their behalf.

## The Mental Capacity Act five key principles:

- 1 Every adult has the right to make his or her own decisions and must be assumed to have capacity to do so, unless it is proved otherwise.
- 2 People must be supported as much as possible to make a decision before anyone concludes that they cannot make their own decision.
- 3 People have the right to make what others might regard to be an unwise or eccentric decision
- 4 Anything done for or on behalf of a person who lacks mental capacity must be done in their best interests – the Act explains how to determine a person's best interests.
- 5 Anything done for or on behalf of a person who lacks mental capacity should be the least restrictive of their basic rights and freedoms, providing it is still in their best interests.

According to the Act, a person's capacity must be assessed on a decision-specific basis. This is to prevent 'blanket' assessment of capacity – just because someone with dementia can't make a complex decision about medical treatment, for example, it should not be assumed that they lack capacity to make a decision about what they eat or wear. The Act also emphasises that assessments of capacity or deciding a person's best interests must not be done on the basis of their age, appearance, condition or behaviour alone.

### A diagnosis of dementia is not a reason for deciding someone lacks capacity.

If you want to get information about how you assess someone's mental capacity there is a free, confidential online tool you can use at:

**[www.amcat.org.uk](http://www.amcat.org.uk)**

If you want to get information about how you decide what is in someone's best interests there is another free, confidential online tool you can use at:

**[www.bestinterests.org.uk](http://www.bestinterests.org.uk)**

# Roles, Bodies and Powers supporting the Act

## Independent mental capacity advocate (IMCA)

The Act creates a new advocacy service – Independent Mental Capacity Advocates (IMCAs). The support people who lack capacity when certain decisions have to be made (including consent to serious medical treatment) and there is no one else to consult. More information about the Act is contained in the Code of Practice, which can be found at <http://www.publicguardian.gov.uk/mca/code-of-practice.htm>

## Advance decisions to refuse treatment

It also allows people to make advance decisions to refuse treatment which are usually legally valid.

## Attorneys appointed under Lasting Powers of Attorney (LPAs)

The Act introduces a new Lasting Power of Attorney (LPA) that allows people over the age of 18 to formally appoint one or more people to look after their health, welfare and/or financial decisions, if at some time in the future they lack the capacity to make those decisions for themselves. The Lasting Power of Attorney replaces the old Enduring Power of Attorney (EPA) although these still remain valid.

## Court of Protection and deputies

The MCA created a new court to protect people who lack capacity, to supervise those making decisions on their behalf, and to deal with disagreements or complex decisions relating to the MCA. The court is able to appoint a Deputy, for example, to make decisions on behalf of someone who lacks capacity. The court will tailor the powers of the deputy according to the circumstances of the individual.

## Office of the Public Guardian (OPG)

The role of the Public Guardian is to help protect people who lack capacity. The OPG maintains a register of LPAs and EPAs. It also maintains a register of court-appointed deputies and is responsible for supervising them.

The Act makes the ill treatment or wilful neglect of a person who lacks capacity a criminal offence.

## The Mental Capacity Act Code of Practice

The code explains how the MCA works on a day-to-day basis and provides guidance to those working with people who may lack capacity. The Code explains the key features of the MCA in more detail, as well as some of the practical steps that people using and interpreting the law need to take into consideration. If you work with people who lack capacity and you are paid for the work you do, then you have a legal duty to regard the Code. It is also relevant to unpaid carers who will be helped and guided by it.

It can be found at:

<http://www.publicguardian.gov.uk/mca/code-of-practice.htm>

A hard copy of the Code can be purchased from The Stationery Office (TSO)

**Tel: 0870 600 5522 / 0870 600 5522**

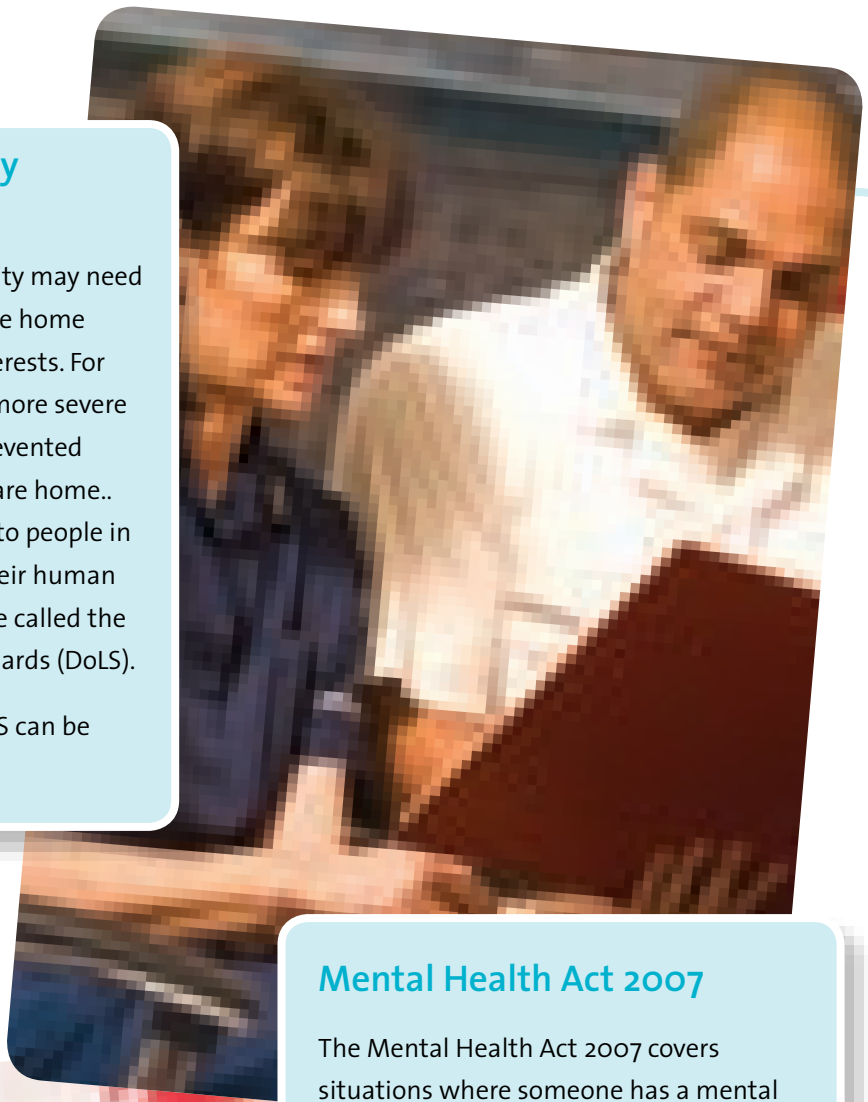
**Email: [customerservices@tso.co.uk](mailto:customerservices@tso.co.uk)**

**Web: [www.tsoshop.co.uk](http://www.tsoshop.co.uk)**

## Deprivation of Liberty Safeguards

Some people who lack capacity may need to be kept in hospital or a care home because it is in their best interests. For example, some people with more severe dementia may need to be prevented from wandering out of the care home.. Extra legal safeguards apply to people in these situations to ensure their human rights are respected. These are called the Deprivation of Liberty Safeguards (DoLS).

More information about DoLS can be found below.



## Mental Health Act 2007

The Mental Health Act 2007 covers situations where someone has a mental disorder and requires treatment because they are a risk to themselves or others. The Act allows them to be compulsorily admitted to hospital and treated without consent, and sets out a number of legal safeguards to ensure their rights are protected. This includes the right to have their detention in hospital reviewed and access to a new advocacy service, the Independent Mental Health Advocacy service (IMHAs).

More information about the Mental Health Act is contained in its Code of Practice which can be found at:

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_o84597](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_o84597)



# Restraint

## What helps reduce use of restraint?

- Make good risk assessments and support residents to ‘take risks’ if they wish to.
- Start care planning from the perspective of exploring what residents can do. This will reduce the need for restraint.

### Have a discussion with colleagues.

- Talk about circumstances where restraint has been needed for residents.
- Make a plan to reduce circumstances when restraint will be needed.
- Use Life Story work to reduce use of restraint.
- Involve relatives in discussions and care plans.

### More information:

<http://www.scie.org.uk/publications/atagance/atagance16.asp>

<http://www.scie.org.uk/publications/reports/report26.asp>

Restraint can be a difficult issue in care homes. The word “restraint” means different things to different people. It has been defined as:

**“Anything which interferes with, or stops a resident doing what they appear to want to do.”**

(Clarke & Bright, 2002)

The legal definition from The Mental Capacity Act 2005 states that:

**“Someone is using restraint if they:**

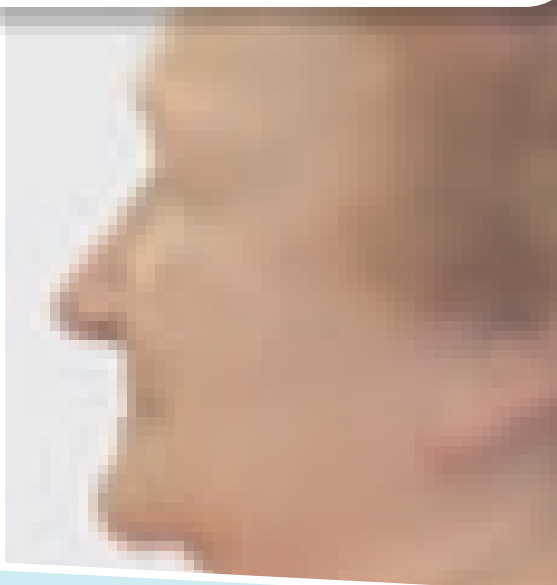
- **use force (or threaten to use force) to make someone do something they are resisting or**
- **restrict a person’s freedom of movement, whether they are resisting or not.”**

## Understanding the link between risk and restraint

Reasons given for the use of restraint in care homes generally relate to a concern for safety or as a response to agitation and aggression.

There are many different ways to describe restraint, ranging from active physical interventions to failing to assist a person:

- You have a duty to minimise the use of restraint, but sometimes it will be the right thing to do.
- Knowing the individual, valuing the views of relatives and working as a team will help reduce the need for restraint.



**The use of restraint is a topic that people can be reluctant to discuss. Talking about it openly will help staff and relatives understand the the care home’s policy and the use of The Mental Capacity Act.**

# Deprivation of Liberty Safeguards (DoLS)

People who suffer from a disorder or disability of the mind, such as dementia or a profound learning disability, and who lack the mental capacity to consent to the care or treatment they need, should be cared for in a way that does not limit their rights or freedom of action. This is in line with the Mental Capacity Act.



However, in some cases members of this vulnerable group need to be deprived of their liberty for treatment or care because this is necessary in their best interests, to protect them from harm. For this group of people an extra safeguard is needed to ensure that this is done lawfully. The aim of the Deprivation of Liberty Safeguards is to provide this legal protection for these vulnerable people.

Whenever a hospital or care home identifies that a person who lacks capacity is being, or risks being, deprived of their liberty, they must apply to the local supervisory body for authorisation of deprivation of liberty. Where a person is in a care home, the supervisory body will be the relevant local authority.

This is done by completing a set of standard forms.

**Applying for a Deprivation of Liberty is not a negative reflection on the care home. Where a deprivation of liberty is appropriately applied for it, it is a way of safeguarding and protecting the vulnerable person.**

There is additional help and support available for family and carers where they need support to deal with this legal process. People who are deprived of their liberty, have a legal right to representation and support from an Independent Mental Capacity Advocate (IMCA).

The Code of Practice for Deprivation of Liberty Safeguards must be read alongside the Mental Capacity Act Code of Practice, as they both apply.

# DoLS and Mr Brown

**Mr Brown suffers from a vascular-type dementia. He has been living at home, cared for by his wife. His daughter visits regularly but has a strained relationship with her mother. Recently, Mrs Brown has begun to struggle with the care of her husband, and she is feeling exhausted. Mr Brown's physical and mental needs are now so great that no amount of effort will make it safe for him to remain at home.**



The CPN calls weekly to support Mrs Brown and to monitor and manage Mr Brown's declining mental health.

Mrs Brown decides that she cannot manage any longer and, after careful consideration, she arranges for her husband to be admitted to a local EMI residential care home. He is funded privately. The CPN agrees that this is in Mr Brown's best interests as it is now very difficult for Mrs Brown to meet his needs.

Mr Brown is initially unsettled at the care home and the CPN visits regularly to support with medication and behaviour management. Mr Brown's daughter is concerned and angry and says that her

father does not require the support of a care home and should have remained with her mother. Mrs Brown is upset by this and communication breaks down. Her daughter continues to insist her father should not be in care and tells the home manager that they are depriving him of his liberty. The home manager is concerned that they may face legal action from Mr Brown's daughter and requests a best interest assessment.

In the meantime, the staff continue to manage Mr Brown's needs. He is accompanied outside when he is restless and wants to go out. His family come to see him often.

The outcome of the DoLS assessment is that there is no deprivation of liberty because:

- a) visitors are not restricted**
- b) Mr Brown is taken out when he requests this**
- c) although the front door of the home is locked, Mr Brown is not locked in his room at any time.**

There are restrictions on Mr Brown's liberty but these are due to a duty of care. The frequency, intensity and nature of the restrictions are not sufficient to constitute a deprivation of liberty.

**This section is intended for for guidance only. Proper training is required and staff should always follow their care home's policies.**

# End of life care

Understanding death and dying



Don't assume people  
don't want to talk.

# Understanding end of life care

Care homes are increasingly at the forefront of good practice in providing care for those who are approaching or reaching the end of their life.

**“How people die remains in the memory of those who live on.”**

*Dame Cicely Saunders – Founder of the Modern Hospice Movement*

As a society we can find it difficult to talk openly about death and dying.

**“Most of us find it hard to engage in advance with the way in which we would like to be cared for at the end of life.”**

*End of Life Care Strategy, Department of Health, 2008*



**1 in 5 of people over 65 die in care homes, so the reality of death confronts anyone working in a care home setting.**

Many people enter a care home because they are no longer able to live independently in their own home. For these people, the care home becomes their normal place of residence and many would prefer to stay there until they die. Others enter a care home for respite care, or for nursing care and rehabilitation, with a view to returning to independent living. Care homes are well placed to provide excellent care to people who are dying – and many do. However, we know that significant numbers of residents are still being admitted to hospital from their care home in the last hours, days, or weeks of life when this is not necessarily their wish, or in their best interests.

Around 70% of people would prefer to die at home, yet of the 500,000 people who die each year in England, around 60% die in hospitals (*Source: Dying Matters NatCen Survey, 2009*).

Improving end of life care is essential. This section gives some ideas of best practice.

“Care homes should ensure that they have appropriate mechanisms and staff in place to identify, assess and plan care for residents who are approaching the end of life. They should work with PCTs to ensure that medical and nursing services....required by people at the end of life are available to their residents.” (*EOLC strategy*)

**The role of care staff in improving end of life care in care homes**

- Enabling residents to die in comfort and with dignity is a core function of care homes and their staff.

**How can care homes improve the end of life care that is delivered?**

- It is important for care homes to develop a culture where death is accepted as an inevitable part of life and a good death in the care home is seen as positive care.
- Residents are supported to accept a death within the home and helped to grieve.
- Death, dying and end of life care and advance care planning are discussed openly with residents, families, friends and staff.
- The care home supports the spiritual and religious needs of residents.
- The care home supports the training of all staff in end of life care to ensure that they are skilled to review and manage symptoms and promote effective pain control.
- The care home manager and staff have good relationships with family members.
- The care home manager develops positive relationships and open communications with NHS services – that is, the resident’s GP, the community palliative care team and the medical out of hour’s team. This will help to prevent unnecessary crisis admissions to an acute hospital or A&E department.

# TOP TIP

## Keep the GP and family informed

- It is a good idea to ensure residents are reviewed regularly by the GP and that plans about end of life care are discussed with the GP.
- It is also very important to keep the family informed as they should normally be active participants in this process and may, for example, want to stay with their relative.

### Some common challenges in end of life care include:

- end of life care not being discussed with residents and their families, with a consequent lack of advance care planning
- difficulty in recognising when end of life begins and a failure to undertake, or arrange for, an holistic assessment of the person's needs and preferences
- concerns in some care homes that when residents die there it may reflect badly on how other people see the quality of care provided
- concerns about the impact on other residents of people dying in the care home
- difficulty in accessing or lack of NHS services – for example, district nursing care, primary medical care, out of hours (OOH) medical care, community palliative care teams;
- inadequate review and management of symptoms, problems and medicines (for example, pain control)
- inadequate training of staff at all levels
- pressure to show that “everything possible” was done, to reassure families and others
- not always recognising the need to support the person's spiritual and/or religious needs (See Quality of Life section – Faith and Spirituality).

### Although every individual may have a different idea about what would, for them, constitute a ‘good death’, for many this would involve:

- being treated as an individual, with compassion, dignity and respect
- being without pain and other symptoms;
- being in familiar surroundings, and
- being in the company of close family and/or friends.
- most would probably like to die at home

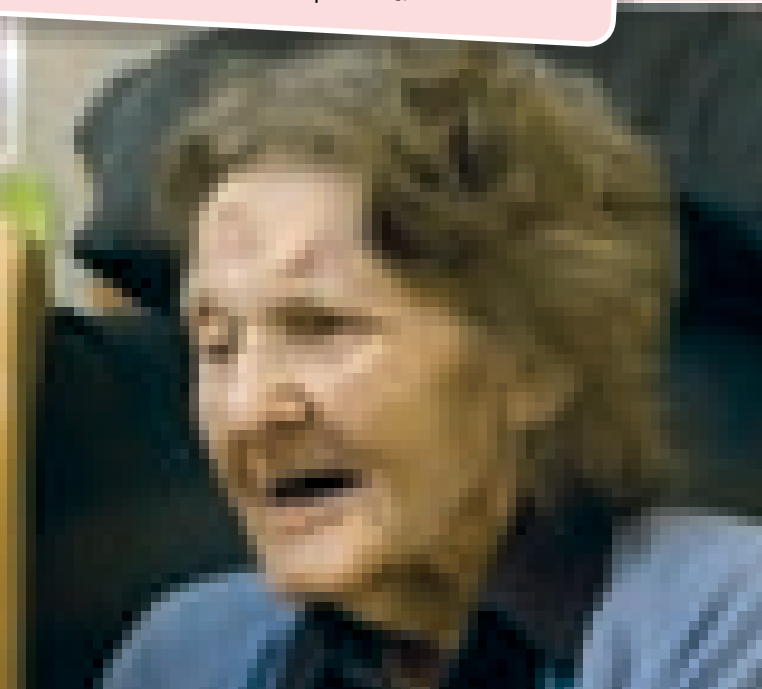
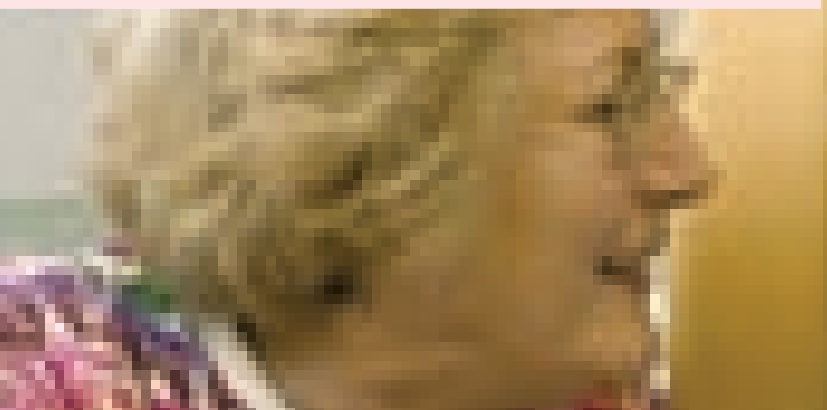
However, if people are to have a choice about where and how they die, they need to be having conversations about this. Given the current cultural taboos around such conversations, it is not surprising that we find this a challenge.

One of the key challenges for managers and staff is knowing how and when to open up a discussion with an individual resident, their family and friends about what they would wish for as they near the end of their life.

### When planning care, agreement needs to be reached on:

- when discussions should occur,
- who should initiate them, and
- what skills and competencies staff requires to take on this role.

This can be challenging work and self-care for staff members is vitally important.



# MYTH

“If I talk about his illness, I will only upset him more.”

## Dissolving myths

It's a common belief that talking about someone's illness or impending death will only upset them. Many people are surprised to find that a dying person wants to talk about what's happening to them. In fact, many dying people are thinking the same thing – that talking about what's happening to them will only upset their friend or loved ones.

**However we do not always know how to have these conversations.**

There is no right way or wrong way to talk about dying. No one finds it easy to talk when they're rushed or in a stressful situation. Take your cue from the other person.

## How to start a conversation

You can encourage people to talk more about their feelings by saying things like:

- How are you feeling?
- You must be feeling a lot of emotions at the moment
- Is there any one thing worrying you the most?
- Do you feel frightened?
- Is there anything you want to talk about?
- Do you worry at night?
- Is there anything that helps you feel calm?

## Try not to:

- offer advice – things you might find helpful may not suit others.
- use expressions like “I know exactly what you mean” or “I have felt like that before”.
- if a resident tells you they are scared, don't tell them not to worry because they will still worry but won't tell you.
- ask for specifics – people often fear the process of dying and worry how those they love will manage afterwards.

## Ask “How can I help?”

## How can I listen and be non-judgemental ?

- The dying person may be angry, resentful, scared, sad, resigned, accepting or some combination of all.
- Do not judge what the person is feeling, because that will probably stop the conversation in its tracks or make them angry.
- Many people find it hard to listen to people who are dying because in our society people always feel like they have to fix problems.

In reality nobody can fix this problem – but letting someone who is terminally ill express his or her feelings without fear of judgement does help. If the person is angry, let him express it. Do not try to talk him out of his feelings. It's best to just acknowledge how he or she is feeling.



## Creating the right atmosphere helps

- Eliminate all the distractions, such as radio, television etc. set an atmosphere that is calm and peaceful.
- Talk to the person at the same eye level. Avoid standing beside him/her. Instead, sit near him/her, so that he/she has no difficulty in talking or listening to you.
- Control the volume of your conversation. At the same time, let the dying person set the pace of the conversation.
- You should not expect a dying person to be energetic. He/she may have very little energy. You need to keep asking him/her, if he/she needs a break from the conversation and wants to rest.
- He or she may want to reminisce his/her golden period of life. Talk about the significant events of his/her life. Knowing them from the Life Story work you have done will prove invaluable. Sharing happy thoughts with the may help distract him or her from the current situation.
- A dying person may show various emotions. He/she may get angry, guilty or even afraid of facing death. Comfort the person. Allow him/her to express how the feel.
- You don't have to answer or question a dying person. All you need to do is lend an ear and listen to him/her carefully, with patience, showing interest as well.
- This stage of life may bring about fear and anxiety in a person. Hence, you need to show courage while talking to the dying person. Show a smiling face, instead of getting emotional.

**This can be challenging work and self-care for you and other staff members is vitally important. This work can bring up feelings of our own losses, our feared losses and our own death (see section – Am I OK?)**

## Complex issues

**People with a diagnosis of dementia or learning difficulties or both have even more complex needs.**

People with dementia and learning difficulties will die with the disease but will invariably have other physical problems as well. Some of these new symptoms may be masked by the dementia.

It may be hard to recognise changes that indicate nearness to death as dementia and learning disabilities can mask symptoms.

Extreme problems with communications and a lack of knowledge or recognition can contribute to the under-treatment of pain and other symptoms and at its worst promote the use of unnecessary, invasive interventions such as artificial feeding and hydration during the last hours or days of life.

## The role of care staff

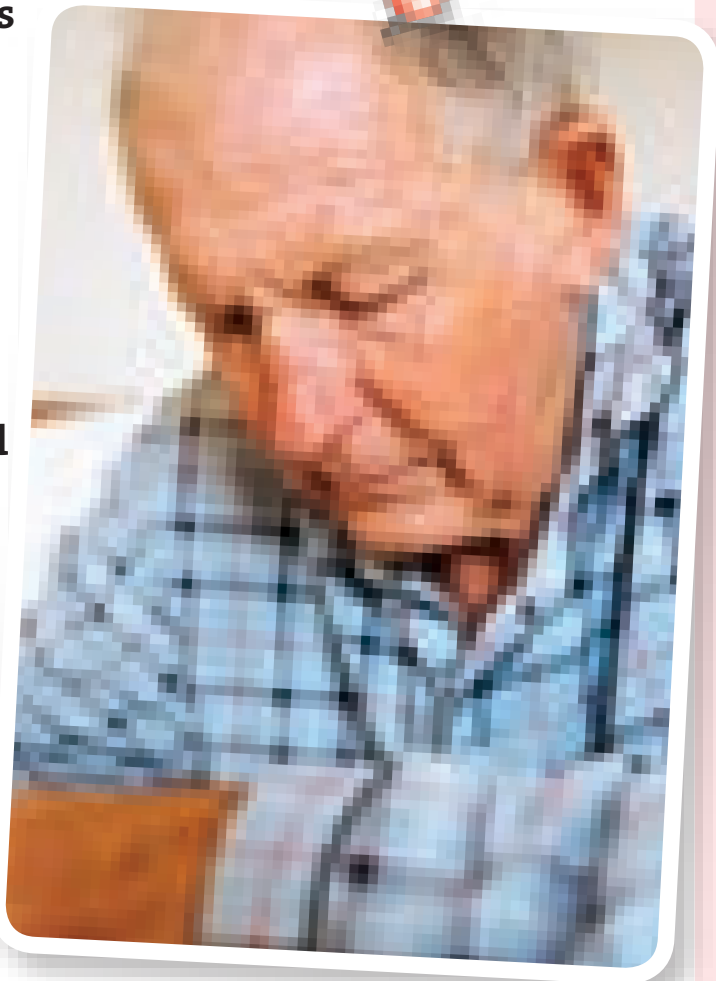
**Care home staff have a most important role and must act as the resident's advocate. They must draw on their knowledge of the Life Story work and their relationships with the resident's family and friends to give them support and at the same time promote feelings of safety and security for the resident to allow them to relax as they withdraw from life.**

## Pain relief

**Care staff will need to take the responsibility for recognising that the resident is receiving the appropriate amount of pain relief by identifying signs of pain and discomfort (see main section on pain in Quality of Life section).**

# Mr Jones's story

Mr Jones (George to his friends and family) suffered from Alzheimer's disease and had been diagnosed with cancer of the oesophagus. Mr Jones was diagnosed rather late in his illness because of communication difficulties. He had, for a long time, patted the back of his neck and became fixated on having cream rubbed in all day. An observant doctor realised that something was wrong when Mr Jones seemed to be having more difficulty eating and he was referred to the specialist.



## LEARNING POINTS

- Pain can be difficult to recognise.
- It is important to know the person.
- You can ask people about pain but observation can be vitally important.

Although the cancer was in his throat, Mr Jones had been indicating a problem with his neck because he was unable to explain where the pain really was. Once the problem was understood he could have proper pain control and the right kind of care. This meant he had painkilling patches as he could not swallow and his pain could be kept under control.

He started a soft diet and drank thickened fluids and was helped to eat little and often because he could not tolerate large amounts. As he became weaker and unable to communicate at all, staff made sure he had his favourite music playing softly so he did not feel alone. Mr Jones got to the stage where he could not eat or drink at all and he spent all day asleep. The staff spent time with his wife helping her to understand that he was "withdrawing from life" and that, although this was very difficult to accept, his main need was now to feel safe and comfortable.

He died with his family beside him.

## What makes a good death?

Although every individual may have a different idea about what would be a good death, for many this would involve:

- being treated as an individual, with dignity and respect
- being without pain and other symptoms
- being in calm, familiar surroundings
- being in the company of close family and friends and familiar staff

Most people would probably like to die at home.

## REMEMBER

- 1 Don't assume people don't want to talk. Often people do.
- 2 Be sensitive to the person's feelings.
- 3 Help the person to be remembered.
- 4 Encourage the person to tell you what they're afraid of, even if it's hard to talk about.
- 5 Don't dismiss your own fears. They matter, too.

*(Adapted from Dr. Darrell Owens, founder and director of the palliative care consult service at Harborview Medical Center)*



# Resources: Death and dying

- nmhdu on-line resources link:  
**www.nmhdu.org.uk**
- **www.ncpc.org.uk/publications**
- **www.lcp-mariecurie.org.uk**
- **www.alzheimers.org.uk**
- **www.rememberingpractices.com**
- *How to talk to a dying person: What to say to the terminally ill during the dying process* [http://caringforfamilymembers.suite101.com/article.cfm/how\\_to\\_talk\\_with\\_a\\_dying\\_person#ixzzoz3ZVgIPv](http://caringforfamilymembers.suite101.com/article.cfm/how_to_talk_with_a_dying_person#ixzzoz3ZVgIPv)
- Hughes.J.C. (2006) *Palliative Care in Severe Dementia*. MA Healthcare Ltd.
- NICE and SCIE. (2006) *Dementia: supporting people with dementia and their carers in health and social care*. London. National Collaborating Centre for Mental Health.
- Small, N., Froggatt,K., Downs, M. (2007) *Living and Dying with Dementia - dialogues about palliative care*. London Oxford University Press.
- Kaiser, P. (2008) *You Say Goodbye and I Say Hello: Narrative therapy and remembering practices with older people*. BPS Faculty of old age psychology newsletter: **www.psige.org/newsletters**

A photograph of a man and a woman sitting at a round wooden table in a bright, modern interior. The man, on the left, is wearing a white short-sleeved shirt and dark trousers, leaning forward slightly. The woman, on the right, is wearing a light purple button-down shirt and is seated in a red armchair, smiling at the camera. On the table are two yellow mugs and a small white container. Large windows in the background let in natural light.

# Staff health

Staff health and wellbeing

**“Working with dementia care can be emotionally taxing and therefore you too will need to be supported throughout the journey”**

# Wellbeing at work – **how do I feel?**

**Our mental health is as important as our physical health. Your workplace can promote and support mental wellbeing and individuals can take responsibility for taking care of their own mental wellbeing. In doing so, employees find their mood improves; they get along better with colleagues and can concentrate better. Promoting mental wellbeing is positive for everyone. Mental health is a positive attribute and something we all have.**

Like physical health, we need to protect our mental wellbeing. In promoting our mental wellbeing – for example, by promoting physical activity, and providing opportunities for relaxation and social activities – we can increase our resilience to cope with life's difficulties and our ability to enjoy life.

When we are mentally healthy, we are more likely to fulfill our potential, function well, cope with and enjoy work, family and social relationships and to make healthy choices about our lives.

The workplace can make a positive contribution to promoting the wellbeing of staff by creating the right environment and management structures.

- **Better job satisfaction.**
- **Better communication with colleagues.**
- **Better relationships with colleagues.**
- **Improved health.**
- **Reduced stress and anxiety.**
- **Lower rates of absenteeism and a quicker return to work after illness.**
- **Fewer injuries in the workplace.**
- **Improvements in communication, morale and working atmosphere.**
- **A positive image.**

It is recognised that stress in the workplace is a serious issue that can cause individuals to suffer clinical symptoms, both mental and physical. This in turn can impair the productivity of an organisation and the care that you can give.

## What is stress?

“The adverse reaction people who have excessive pressure or other types of demand on them.” (*The Health and Safety Executive*)

There are good and bad sides of stress – some people thrive in stressful situations, while others find them distressing. Stress is experienced differently by everyone and we can all benefit from understanding more about stress by identifying the stressors in our own lives and finding ways to reduce them.

## What causes stress?

Stress can be caused by pressure at home or work and there are many different causes, some of which are listed here:

- financial problems and pressures.
- work related issues e.g. deadlines, workload, colleague relationships.
- bereavement.
- change or uncertainty.
- relationship troubles.
- moving house.
- changing jobs.
- heavy traffic.

There are many things you can do to protect yourself against stress and its harmful effects.

## Dealing with burnout: The ‘Three R’ approach

- **Recognise** – Watch for warning signs of burnout.
- **Reverse** – Undo the damage by managing stress and seeking support.
- **Resilience** – Build your resilience to stress by taking care of your physical and emotional health.

## The difference between stress and burnout

Burnout may be the result of unrelenting stress, but it isn’t the same as too much stress. Stress, by and large, involves too much – too many pressures that demand too much of you physically and psychologically. Stressed people can still imagine that, if they can just get everything under control, they’ll feel better.

Burnout on the other hand, is about not enough. Being burned out means feeling empty, devoid of motivation, and beyond caring. People experiencing burnout often don’t see any hope of positive change in their situation. If excessive stress is like drowning in responsibilities, burnout is being all dried up. One other difference between stress and burnout: while you’re usually aware of being under a lot of stress, you don’t always notice burnout when it happens.



## Stress vs. Burnout

### Stress

- Characterised by over-engagement.
- Emotions are over-reactive.
- Produces urgency and hyperactivity.
- Loss of energy.
- Leads to anxiety disorders.
- Primary damage is physical.
- May kill you prematurely.

### Burnout

- Characterised by disengagement.
- Emotions are blunted.
- Produces helplessness and hopelessness.
- Loss of motivation, ideals and hope.
- Leads to detachment and depression.
- Primary damage is emotional.
- May make life seem not worth living.

*Source: Stress and Burnout in Ministry*

**“The emotional work of looking after others can be rewarding but also challenging – not just physically with needing to know about lifting and handling, but also emotionally.”**

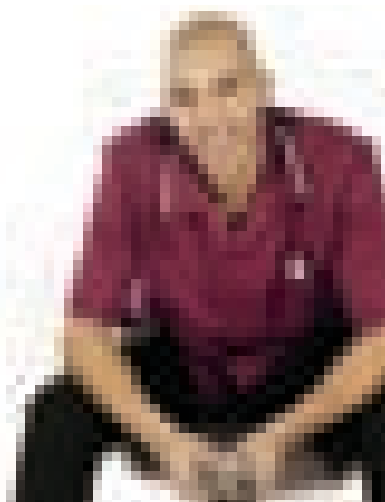
Working with dementia care can be emotionally taxing and therefore you too will need to be supported throughout the journey.

It is important to develop a culture where it is acceptable to express emotions at work. Expressing affection and happiness, letting others know that you feel their hurt/pain and offering support and understanding is important for development. Positive dementia care usually takes place in an environment where both the person with dementia and the person caring for them are able to feel comfortable about expressing emotions, and where people can be supported in expressing negative feelings safely.

People will need to be in touch with their own feelings in order to understand how the people they support may be feeling and this can be challenging.

**Some of the feelings people may experience are:**

- grief
- sadness
- loss
- anger
- joy
- concern
- happiness
- guilt
- denial
- distress.



Support can be gained through a variety of different ways.

**Encourage the sharing of feelings at:**

- mealtimes
- breaks
- workshops
- one-to-one supervision
- team briefings/meetings
- support groups.

Managers/leaders can let staff see that it's ok to be yourself at work: be real, be there for staff, lead by example, listen, acknowledge and be a human being!!!

**“As we let our own light shine, we unconsciously give other people permission to do the same.”**

*Nelson Mandela*

## 5 ways to wellbeing...

### 1 Connect

Connect with the people around you. With family, friends, colleagues and neighbours. At home, work, school or in your local community. Think of these as the corners of your life and invest time in developing them. Building these connections will support and enrich you every day.

### 2 Be active

Go for a walk or a run, step outside, cycle, play a game, garden or dance. Exercising makes you feel good. Most importantly, discover a physical activity you enjoy and one that suits your level of mobility and fitness.

### 3 Take notice

Be curious. Catch sight of the beautiful. Remark on the usual. Notice the changing seasons. Savour the moment, whether you are walking to work, eating lunch or talking to friends. Be aware of the world around you and what you are feeling. Reflecting on your experiences will help you appreciate what matters to you.

### 4 Keep learning

Try something new. Rediscover an old interest. Sign up for that course. Take on a different responsibility at work. Fix a bike. Learn to play an instrument or how to cook your favourite food. Set a challenge you will enjoy achieving. Learning new things will make you more confident as well as being fun.

### 5 Give

Do something nice for a friend, or a stranger. Thank someone. Smile. Volunteer your time. Join a community group. Look out, as well as in. Seeing yourself, and your happiness, linked to the wider community can be incredibly rewarding and creates connections with the people around you.

# Resources: Are you OK?

Here is a list of a variety of resources. You may not need any of them, or you may know people who do.

- Health and Safety Executive (2001). *Tackling work-related stress: a manager's guide to improving and maintaining employee health and well-being*.
- Johnson, M. (2004). *The new rules of engagement: lifework balance and employee commitment*. CIPD
- Leary-Joyce, J. (2004). *Becoming an employer of choice: making your organisation a great place to work*. CIPD
- Scottish Executive and ADSW (2005), *Improving front line services: a framework for supporting front line staff*.
- Stredwick, J. and Ellis, S. (2005), *Wellness at work*.

## Websites:

### ACAS

- [www.acas.org.uk](http://www.acas.org.uk)
- helpline 08457 47 47 47

### Alcohol

#### Alcohol Concern

Alcohol Concern is the national agency on alcohol misuse. It works to reduce the incidence and costs of alcohol-related harm and to increase the range and quality of services available to people with alcohol-related problems.

- Tel: 020 7264 0510
- [www.alcoholconcern.org.uk](http://www.alcoholconcern.org.uk)

## HEALTH, WORK AND WELLBEING

### Equality issues

**The Equality and Human Rights Commission** – formerly the Equal Opportunities Commission, the Commission for Racial Equality, and the Disability Rights Commission – works to eliminate discrimination, reduce inequality, and protect human rights.

#### Equality and Human Rights Commission (EHRC) Disability Helpline (England)

- Tel: 08457 622 633
- Textphone: 08457 622 644

#### Race, age, gender, sexual orientation, religion and belief and human rights Helpline (England)

- Tel: 0845 604 6610
- Textphone: 0845 604 6620

### EHRC Wales

- Tel: 0845 6048810
- Textphone: 0845 6048820

### EHRC Scotland

- Tel: 0845 6045510
- Textphone: 0845 6045520
- [www.equalityandhumanrights.com](http://www.equalityandhumanrights.com)

### Employer's Forum on Disability

The Employers' Forum on Disability is the leading employers' organisation focused on disability as it affects business. Funded and managed by over 400 members, it aims to make it easier to recruit and retain disabled employees and to serve disabled customers.

- Tel: 020 7403 3020
- [www.employers-forum.co.uk](http://www.employers-forum.co.uk)

### **Shaw Trust**

Shaw Trust is a national charity that provides training and work opportunities for people who are disadvantaged in the labour market due to disability, ill health or other social circumstances.

- Tel: 0800 085 1001
- [www.shaw-trust.org.uk](http://www.shaw-trust.org.uk)
- [www.employersforwork-lifebalance.org.uk](http://www.employersforwork-lifebalance.org.uk)

### **Flexible working**

The right to request and the duty to consider: a guide for employers and employees.

- [www.berr.gov.uk](http://www.berr.gov.uk)

### **Health and safety**

Advice on everything from hazardous substances to musculoskeletal disorders and stress can be found at the Health and Safety Executive:

#### **Health and Safety Executive (HSE)**

- Infoline: 0845 345 0055
- [www.hse.gov.uk](http://www.hse.gov.uk)

**Healthy Workplace Initiative** – jointly sponsored by the Department of Health and the Health and Safety Executive, see:

- [www.signupweb.net](http://www.signupweb.net)
- [www.health-and-work.gov.uk](http://www.health-and-work.gov.uk)

### **Mental health**

Information and advice on a wide range of mental health problems, including depression, anxiety, phobias, bipolar disorder, and schizophrenia.

### **Rethink**

Rethink is the largest national voluntary sector provider of mental health services with 340 services and more than 130 support groups. It helps over 48,000 people every year through its services, support groups and by providing information on mental health problems.

- Helpline: 0845 456 0455
- [www.rethink.org](http://www.rethink.org)
- [www.moodgym.anu.edu.au](http://www.moodgym.anu.edu.au)

### **Mind**

Mind is the leading mental health charity in England and Wales. It campaigns to create a better life for everyone with experience of mental distress.

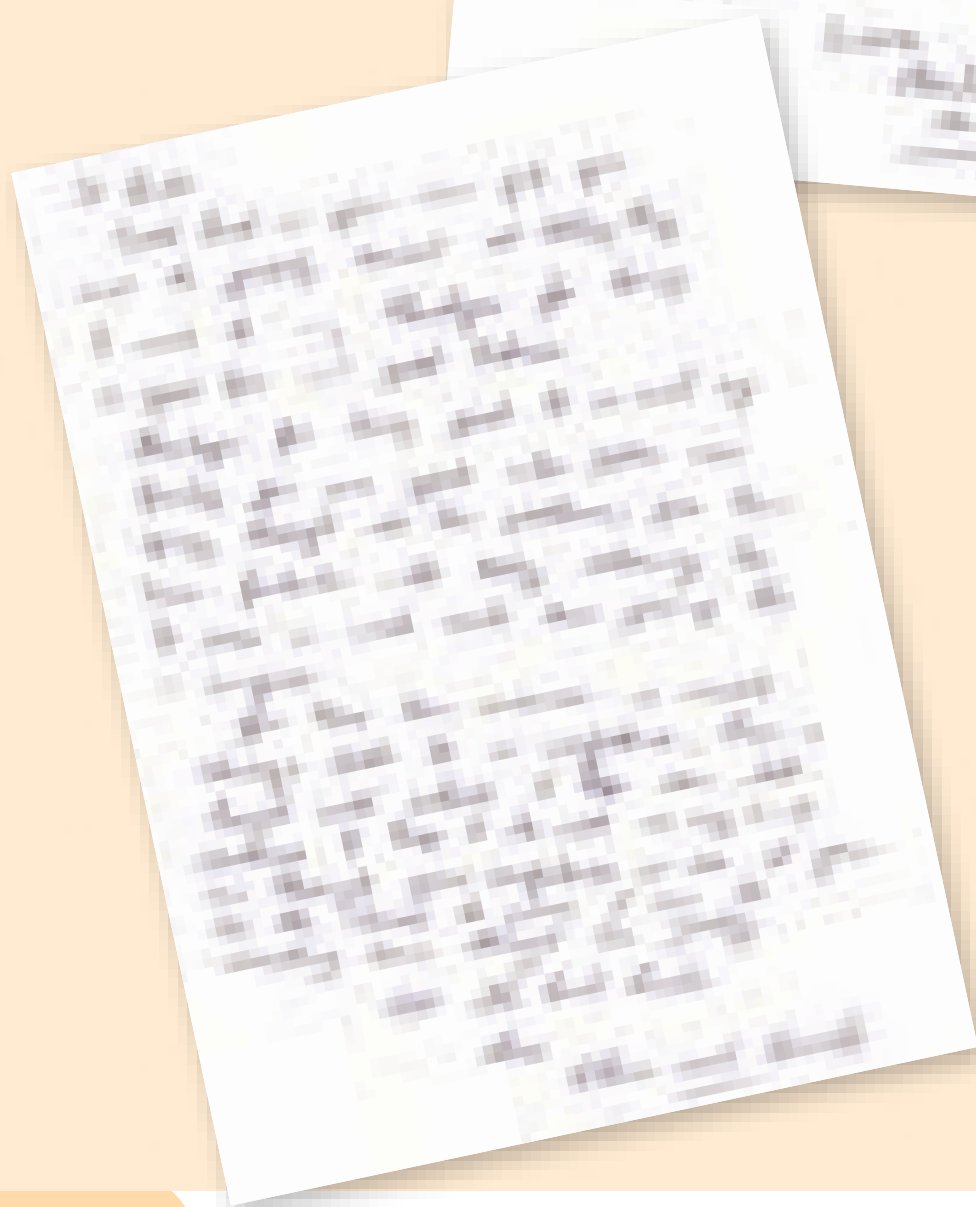
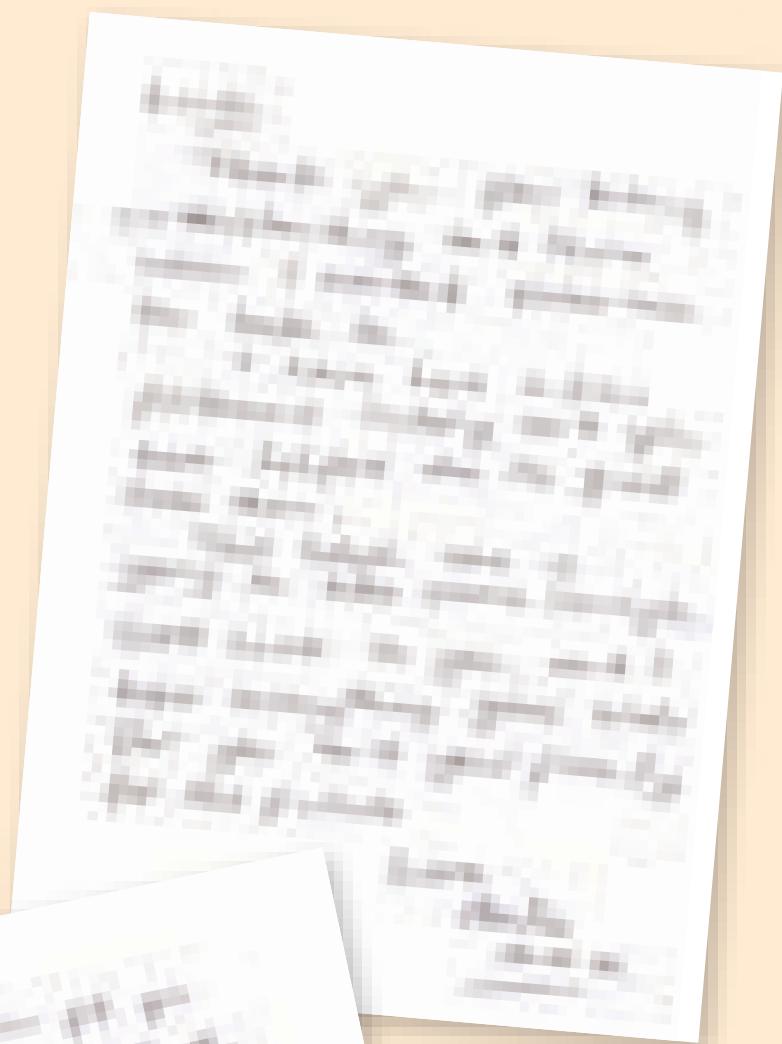
- Tel: 020 8519 2122
- [www.mind.org.uk](http://www.mind.org.uk)

### **The Social Care Institute for Excellence's (SCIE)**

SCIE is an independent charity, funded by the Department of Health and the devolved administrations in Wales and Northern Ireland. SCIE identifies and disseminates the knowledge base for good practice in all aspects of social care throughout the United Kingdom. SCIE's mission is to identify and spread knowledge about good practice to the large and diverse social care workforce and support the delivery of transformed, personalised social care services. We aim to reach and influence practitioners, managers and the sector leadership who have responsibility for service delivery in adults' and children's services.

- [www.scie.org.uk](http://www.scie.org.uk) and
- [www.scie-peoplemanagement.org.uk](http://www.scie-peoplemanagement.org.uk)
- [www.scie.org.uk/publications/dementia/](http://www.scie.org.uk/publications/dementia/)

# Thank you letters received by a care home manager from her staff



# Resources

A photograph of a woman with short, curly blonde hair and glasses, smiling warmly. She is wearing a purple long-sleeved shirt with white piping on the collar and cuffs. She is seated at a desk, with a laptop in front of her. The background is slightly blurred, showing an indoor setting with a lamp and some papers.

“Live as if you were going to die tomorrow.  
Learn as if you were going to live forever.”

*Gandhi*

# Resources

## **The link between mental health and healthy eating**

[www.mentalhealth.org.uk/publications/?entryid5=43900&char=H](http://www.mentalhealth.org.uk/publications/?entryid5=43900&char=H)

## **The benefits of exercise on mild to moderate depression**

[www.mentalhealth.org.uk/publications/?entryid5=38569&char=E](http://www.mentalhealth.org.uk/publications/?entryid5=38569&char=E)

## **Mental health and spirituality**

[www.mentalhealth.org.uk/publications/?entryid5=51515&q=0%c2%acspirituality%c2%ac](http://www.mentalhealth.org.uk/publications/?entryid5=51515&q=0%c2%acspirituality%c2%ac)

## **Mental health and alcohol**

[www.mentalhealth.org.uk/publications/?entryid5=64463](http://www.mentalhealth.org.uk/publications/?entryid5=64463)

## **Dealing with fear and anxiety**

[www.mentalhealth.org.uk/publications/?entryid5=43110&p=9&char=ShowAll](http://www.mentalhealth.org.uk/publications/?entryid5=43110&p=9&char=ShowAll)

## **Mental health problems and friendship**

[www.mentalhealth.org.uk/publications/?entryid5=43993&p=10&char=ShowAll](http://www.mentalhealth.org.uk/publications/?entryid5=43993&p=10&char=ShowAll)

## **Smoking and mental health**

[www.mentalhealth.org.uk/publications/?entryid5=47065&p=16&char=ShowAll](http://www.mentalhealth.org.uk/publications/?entryid5=47065&p=16&char=ShowAll)

## **Explaining Dementia to people with the diagnosis**

[www.mentalhealth.org.uk/publications/?entryid5=38738&char=S](http://www.mentalhealth.org.uk/publications/?entryid5=38738&char=S)

## **Explaining Dementia to family carers and friends**

[www.mentalhealth.org.uk/publications/?entryid5=43120&char=B](http://www.mentalhealth.org.uk/publications/?entryid5=43120&char=B)

## **Explaining Dementia to children and young people**

[www.mentalhealth.org.uk/publications/?entryid5=38715&p=2&char=M](http://www.mentalhealth.org.uk/publications/?entryid5=38715&p=2&char=M)

## **Deafness and Dementia**

[www.alzscot.org.uk](http://www.alzscot.org.uk)

[www.scie-socialcareonline.org.uk](http://www.scie-socialcareonline.org.uk)

## **The Social Care Institute for Excellence**

[www.scie.org.uk](http://www.scie.org.uk)

## **Dignity**

[dignityincare.org.uk](http://dignityincare.org.uk)

## **Royal College of Nursing**

[www.rcn.org.uk](http://www.rcn.org.uk)

## **Department of Health**

[www.dh.gov.uk](http://www.dh.gov.uk)

## **Dementia**

[www.dhcarenetworks.org.uk](http://www.dhcarenetworks.org.uk)

## VIPS Framework

Achieving person centred care through the VIPS-framework, involves all levels in the care provider organization. Person centred care requires sign-up to working in this way across the whole care provider organisation if it is to be sustained over any length of time. Particular elements require leadership at different levels. The first element – Valuing – requires leadership from those responsible for leading the organisation at a senior level. The second element – Individual Care – requires leadership particularly from those responsible for setting care standards and procedures within the organisation. The final two elements – Perspectives and Social Environment – require leadership for those responsible for the day-to-day management and provision of care.

Within the book and through many workshops these questions are used as reflection points for

care providers to assess their own practice and in some cases develop action plans for change. Dawn has worked with a number of national providers to assist them in developing in-house tools for culture change using the VIPS framework.

Brooker, D. 2007 *Person-Centred Dementia Care: Making services better*. Jessica Kingsly

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Tel: 01905 542347

<http://ihsc.worc.ac.uk/dementia>

## Ladder to the Moon

Ladder to the Moon is a charity using training, coaching and interactive theatre to improve quality of life in dementia and residential, they use a development model called Relationship Theatre®. The model works with staff to develop three key attitudes (confidence, awareness, and responsibility) and three key skills (communication, initiation, and improvisation), and also offers high quality outcomes for residents and family carers.

The company has been improving the quality of life for older people in care for the past five years, is supported by the Department of Health Innovation and Social Enterprise Investment funds, and has been invited to be a founder member of the National Skills Academy for Social Care.

Email: [relationship@laddertothemoon.co.uk](mailto:relationship@laddertothemoon.co.uk)

Tel: 020 7228 9700

[www.laddertothemoon.co.uk](http://www.laddertothemoon.co.uk)

## The 360 Standard Framework

The 360 Standard Framework (Care Homes) for excellence in person centred care is the first outcome based, quality improvement and practice development framework to deliver and maintain a person centred culture. It improves business performance, occupancy and retention, involving residents, staff and relatives. Underpinning all

service and practice standards, it goes beyond Essential Standards into the resident experience providing evidence for public confidence as well as improving business efficiency.

[www.360fwd.com](http://www.360fwd.com)

# Resources

## The Dementia Services Development Centre, Stirling

Provide comprehensive dementia education and training, consultancy and research services. The Centre's flagship Iris Murdoch Building is a model for dementia friendly design. This open and welcoming environment provides inspiration for the team's work in designing and remodelling care homes for people with dementia. Research into understanding the needs of people and how to support them is central to their work. The Research

Group are members of the University of Stirling who conduct research, their understanding of dementia and related matters.

Their research projects help to improve the quality of life and services for people with dementia and their carers.

<http://dementia.stir.ac.uk/>

## Bradford Dementia Group at the University of Bradford

We can help you in a number of ways to realise the ambitions of this useful tool kit. We are a multi disciplinary and multi professional group based within the School of Health Studies at the University of Bradford with many years experience working alongside care staff and care homes to help them to provide person-centred care for people with dementia. We will bring our internationally recognised expertise in research, education, training and consultancy to support you in doing your best for people with dementia and their families.

One way we help care homes is by providing short training courses in the following areas:

- Person-centred care
- Life story work
- Activities and occupation for people with dementia
- Understanding the brain and behaviour
- End of life care for people with dementia

We are also happy to work with organisation to develop bespoke courses tailored to their needs.

Our practice development tool, Dementia Care Mapping, is an internationally recognised framework which enables staff to assess levels of well-being in their residents with dementia and increases staff awareness of how their own behaviour affects their residents. In our Learning to use Dementia Care Mapping course we prepare staff to use this tool as part of an ongoing review of care.

Our practice development consultancy service helps organizations to identify their development needs and together we design and implement an evidence-based plan to address these needs.

As part of a University we are in a position to offer accreditation for care staff's learning and development. We offer a Foundation degree in dementia care and undergraduate and postgraduate modules in dementia care including the following topics:

- Approaches to dementia
- Person-centred dementia practice
- The experience of dementia
- Practice development and organisational change
- Evidence-based practice

We can also discuss options for providing accreditation for existing programmes of study that are offered in house.

Please let us know how we can help by contacting us on:

Email: [dementia@bradford.ac.uk](mailto:dementia@bradford.ac.uk)

Tel: 01274 233996

[www.bradford.ac.uk/health/dementia](http://www.bradford.ac.uk/health/dementia)



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**The Art of Design Ltd**

All of the team.

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