NHS
Royal Free London
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The Royal Free London dementia handbook

world class expertise ◆ local care

Receiving a diagnosis of dementia can be a life-changing experience for the person receiving the diagnosis and those who love and care for them. Sometimes this diagnosis can be met with trepidation or it might be a relief to have an explanation for the changes and experiences that may have been increasing over time.

Learning about dementia

Understanding an illness is the first step to understanding the best ways to help a person. Understanding the individual with the diagnosis is also crucial because everybody who has dementia experiences it in a way that is unique to them.

Many websites and organisations offer information, support and advice to carers of people with dementia. Some also have online discussion areas where carers can anonymously discuss difficulties and ask questions from other people in the same position. This peer support can be very helpful to carers.

Key online resources include:

- Age UK
- Alzheimer's Society
- Carers Trust
- Dementia UK

You might also be able to get further support and information from your GP, the memory clinic that diagnosed the person you care for and social services.

About this guide

Hospital can be a stressful place for you and the person you care about. Although we try our best to explain things clearly, we know that our system is complex and can be hard for carers to navigate. We have produced this guide to help demystify the hospital experience, support carers and to show how we can work together for the best outcome for your loved one.

If you have any questions or concerns about your loved ones care, please do not hesitate to speak to a member of staff who is looking after your loved one.

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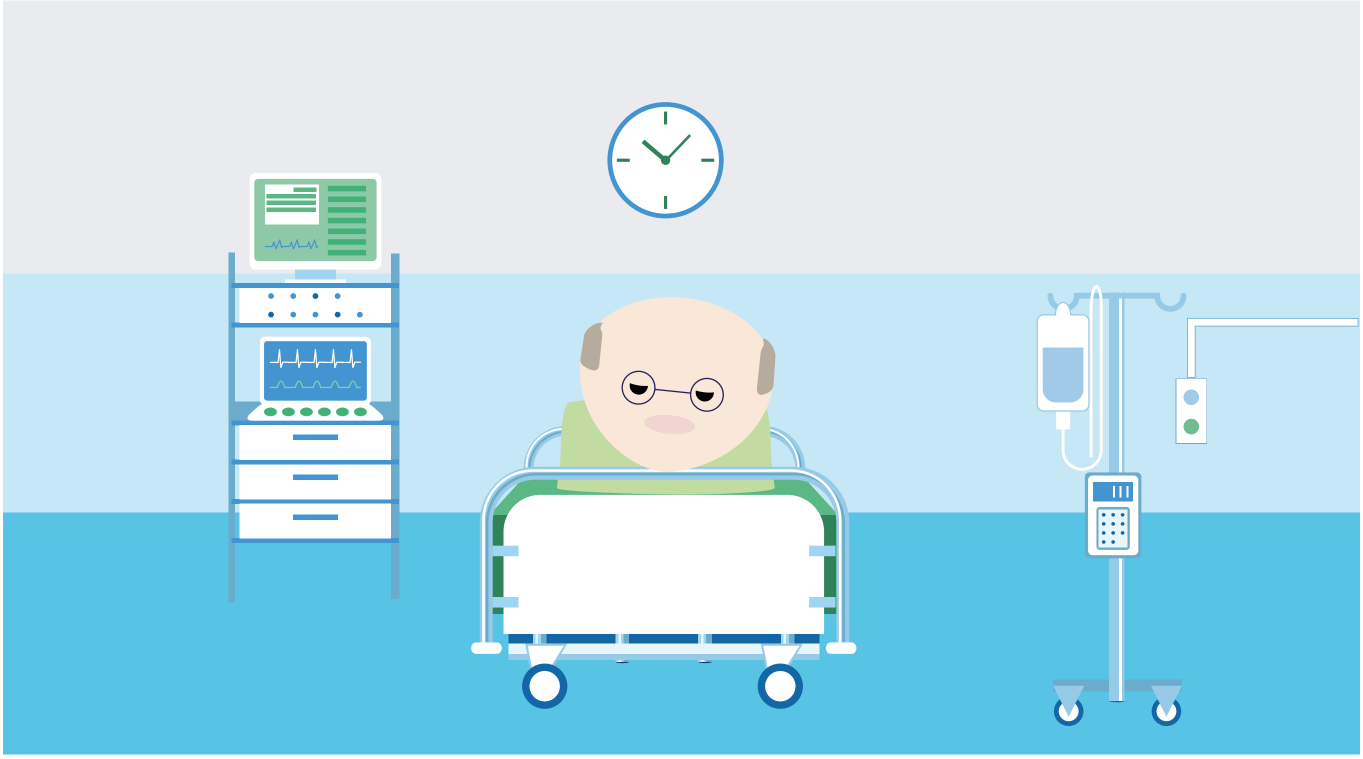
Chapter 1 What to bring into hospital

Having dementia increases the likelihood of a person being admitted into hospital, so it's important to be prepared for an emergency or unplanned situation.

When a woman is 36 weeks pregnant, her treating team recommend that she packs a hospital admission bag that can be left by the front door in the event of an unplanned admission into hospital. A similar approach can be used when caring for a loved one with dementia; being ready for an unplanned hospital admission can help to make a difficult time a little less stressful and help ensure you have all the right things your loved one needs to adjust to the hospital environment.



Here are some key things to bring in for your loved one:

Clothes:

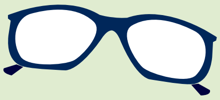
- pyjamas and comfortable clothing including dressing gown
- cardigan or fleece jackets for warmth
- outfit for day of discharge including outdoor coat and weather appropriate clothes and shoes

Dentures:

- dentures and denture pot labelled with the person’s name and date of birth
- denture brush and adhesive
- any specific instructions for use

Footwear:

- socks
- well-fitting trainers or solid slippers for walking with a good grip



Glasses:

- glasses
- glasses case (labelled with name and date of birth)
- cleaning cloth
- instructions for use (for example, for reading or all the time)

Hearing aids:

- hearing aids in a labelled box (left and right aids, labelled with the person’s name and date of birth)
- instructions for use

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In addition to this, the following things are particularly important to pack for people with dementia:

The right information

It may help to have a file or folder that contains certain personal and medical information that can be shared to help our hospital team care for your loved one.

You may find it helpful to use a prompt tool such as the free document produced by the Alzheimer's Society called "This is Me".

Key information should include:

- known medical conditions
- medication usually taken
- information about the home environment (eg what type of property does the person live in, do they have stairs, who do they live with)
- information about the person's usual abilities (eg how they walk, their usual daily routine, what tasks they can do for themselves and tasks they need help with)
- information about the person's support network (eg who provides support for them and what is the level of support provided)
- information to help our staff get to know the person for example the person's preferred name, what job they used to have, what matters to them, as well as any tips for calming them down or engaging them in activities.

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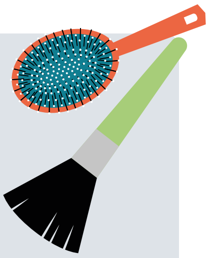
Wash bag with familiar items



In hospital there are staff who are able to assist with all aspects of patient care as required. Although it is good to know that help is available when needed, it's important to strike a balance between having help and maintaining independence.

Where possible, people with dementia who are in hospital should be encouraged to do whatever they can for themselves as it is easy for them to become reliant on care and lose some of the skills (for example, washing and dressing) that they came into hospital with. Packing familiar toiletries can increase a person's ability to do more for themselves and maintain their own routine.

Key items could include;

- comb and hair ties
- favourite soap or shower gel
- razor and shaving cream
- toothbrush
- deodorant
- perfume or aftershave
- make-up or other pampering items to promote well-being such as hand cream

Familiar objects

A person with dementia may rely on familiar objects and items to prompt them about where they are and whether or not they feel safe. Strategic use of familiar objects in hospital can make an unfamiliar environment more recognisable to the person with dementia and reduce the likelihood of them feeling disorientated or distressed. The objects you choose will vary depending on the individual needs and wants of the person with dementia but might include some of the following;

- A favourite blanket or cuddly toy
- Copies of meaningful photographs that staff can use to spark conversations
- Newspapers, magazines or books
- Music/ radio with headphones

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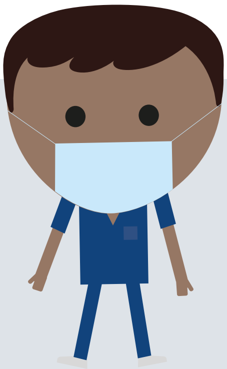
Chapter 2 Who's Who

When a person is admitted into hospital, they are cared for by a multidisciplinary team (MDT) of healthcare professionals, each with different expertise and specialist skills. Carers are an essential part of the MDT so please make sure that you introduce yourself to the relevant people.

The MDT can consist of:



Doctors

Patients will be under the care of a consultant (a very senior doctor) who is responsible for the overall management of their care. The consultant will usually have a team of more junior doctors who will see the patient more frequently during daily ward rounds. During ward rounds the junior doctors, led by the consultant, do a review of their patients, checking test results and updating treatment plans for the day.

Nurses

Nurses are responsible for the day to day running of the ward and delivering the daily care plans for the patients. They regularly monitor a patient's vital signs to ensure that a person is recovering and that their care plan is the right one. Nurses are also responsible for administering medication and supporting patients with their personal care and eating and drinking.

There may be several different types of nurses working on our wards including:

- Staff nurse – a general nurse working on the ward, this person will often be looking after a number of patients during their shift.
- Ward Sister – is the ward manager and nurse in charge. This is usually the best person to ask about discharge plans or any other issues that come up on the ward.
- Matron – is the manager of the ward sisters and will generally cover a larger area (for example several wards) but can be on hand for specific problems or issues if these cannot be resolved by the ward sister.
- Specialist nurses (eg dementia nurse, tissue viability) – specialist nurses cover a range of areas and will be the experts in that field. Other specialities may also be involved depending on the reason for admission.

Nursing Assistants

Nursing assistants usually spend the most one-to-one time with your loved ones. They will help out with personal care and feeding, which makes them a really good source of information about how your loved one has been during their shift.

Occupational Therapist (OT)

An OT assesses a person's 'functional ability' which means their ability to perform tasks ranging from going to the bathroom to making a cup of tea. They start by understanding a person's 'baseline' which means their usual level of ability prior to admission into hospital. Assessing a person's abilities once they are in hospital allows the OT to compare a person's current level with their baseline. If there are any changes in functional ability, the OT can help compensate for and improve functioning using a mixture of adaptive aids and strategies.

An OT might ask to make a home visit to assess what the person's needs might be once they return home. An OT should be able to provide you with equipment to improve independence at home and this may be provided on either a short-term or long-term basis. Examples of equipment include a raised toilet seat, grab rails or equipment to get in and out of the bath.

Physiotherapist (PT)

A PT assesses a person's ability to mobilise (walk) and transfer (move from one position to another, for example, sitting to standing). The PT takes information about the person's previous level of mobility and compares that to how they are currently mobilising. If that person is not as mobile as they were prior to coming into hospital, the PT may provide a mobility aid, for example a walking stick or Zimmer frame, and exercises to follow to improve strength and balance. PTs are often able to diagnose musculoskeletal problems by analysing a person's walking pattern (known as a "gait") as well as manage the risk factors that contribute to falls.

Speech and Language Therapist (SLT)

A SLT works with difficulties that a person may experience in relation to their communication, or their swallowing during eating and drinking. As a person's dementia progresses they may experience difficulties these things. SLT's can assess and diagnose a communication or swallowing difficulty and may be able to advise on strategies to help.

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Dietitian

As a person's dementia progresses, they may experience changes to their appetite, their attitude towards food and drink and even changes in preferences that they may have always had. People may find remembering to feed themselves or the actual act of feeding more complicated and, as a result, malnourishment and weight loss are a common problem in people with advancing dementia. A dietitian is an expert in food and nutrition and the MDT may refer to them to look at whether or not a patient's diet can be altered to minimise the risk of malnourishment and ensure that they are having as many calories and vitamins as possible. This may involve reviewing the types of meals a person eats and how often or it might involve prescribing supplement shakes or juices.

Ward Clerk

Ward clerks are the front of house members of staff on the ward. Generally they will be the team member who answers the phone, send out letters and book transport for patients who are being discharged.

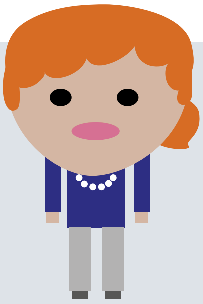
Housekeeper

Housekeepers manage the day to day logistics of the ward including stock levels and food and drink. Often housekeepers will be responsible for helping patients order their food from the menu and serving tea and coffee so they may be a good person to tell about any food and drink preferences or eating habits.

Domestics

Domestics keep the ward clean and tidy and often spend a large part of their shift in the same areas as patients. This means that even though they are not clinical staff, they do spend a lot of time face to face with patients and can sometimes pick up on helpful things about the patient.

Dementia Lead



The dementia lead is a senior specialist who is available to support and give advice to families and ward staff involved in the care of people with dementia.

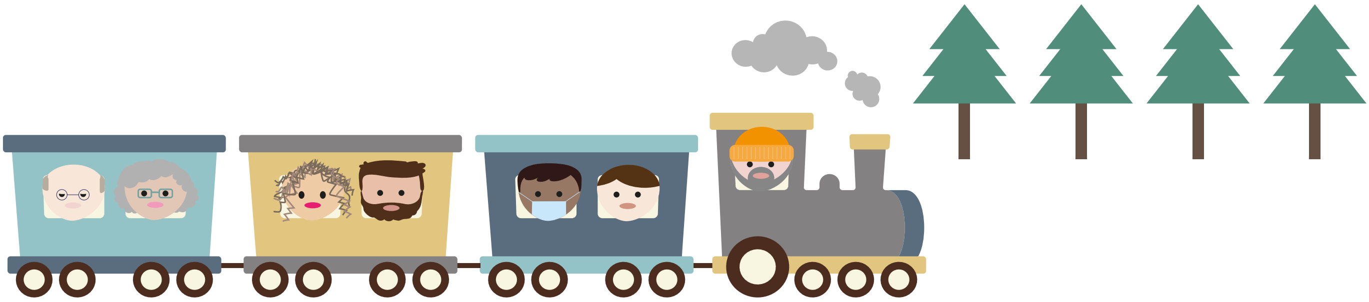
At the Royal Free London our dementia lead is Danielle Wilde. If you have any questions or concerns you can contact her by email to: daniellewilde@nhs.net

Discharge team

Some wards have a discharge planner who co-ordinates the practical elements of your loved one's discharge from hospital. It is important to know who is responsible for planning your loved one's discharge as carer involvement is crucial in planning a safe and timely discharge from hospital. If there is no discharge team on your ward, it may be a nurse or a therapist who is leading the discharge process. Your ward sister will have oversight of all discharges and any ongoing issues so make sure you ask the ward sister who you should be speaking to about planning the discharge together.

Advice for you

Meeting so many different people can be a bit overwhelming for families and you may find you have to repeat the same information to different people in the MDT – please bear with us we each have our own areas of expertise and the information you provide us with will enable us to provide your loved one with the very best care.



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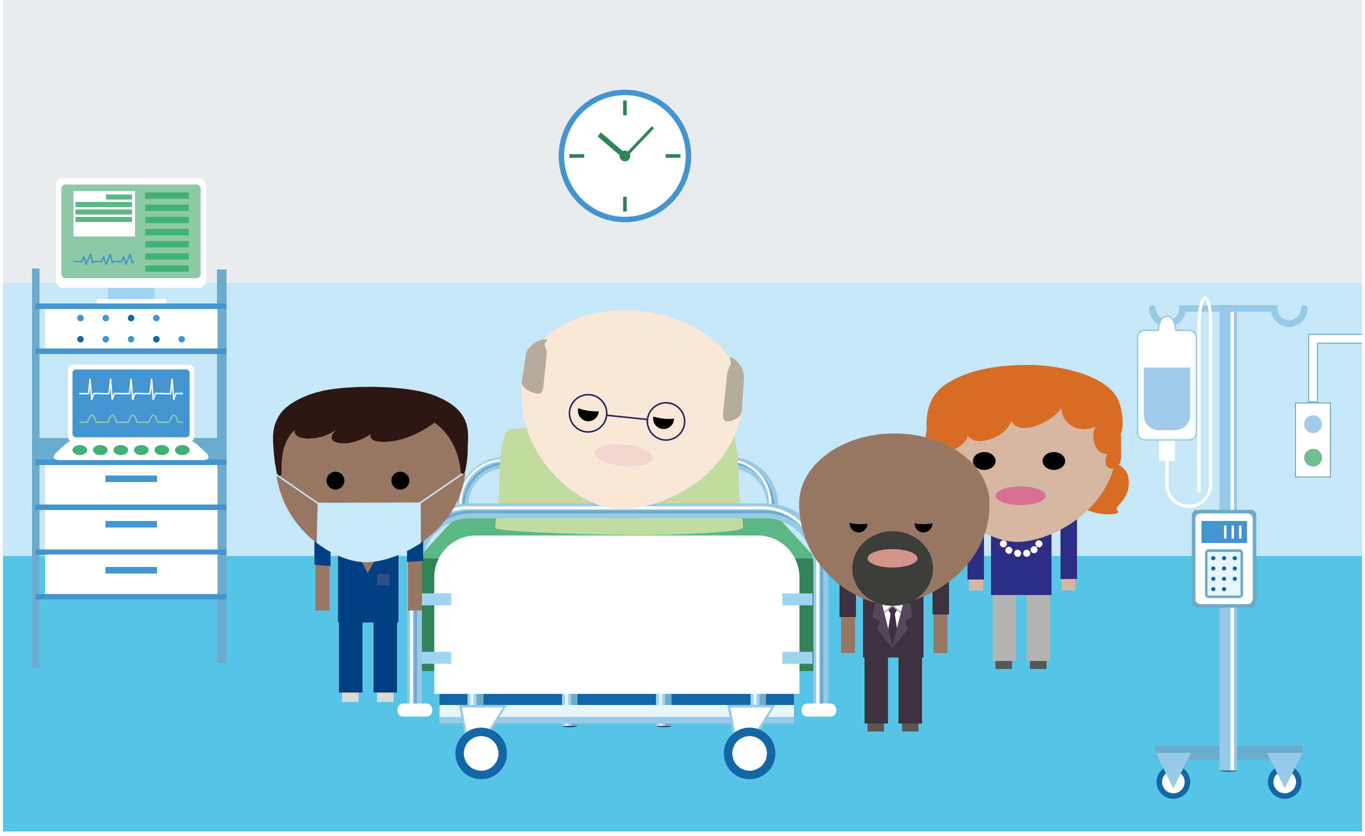
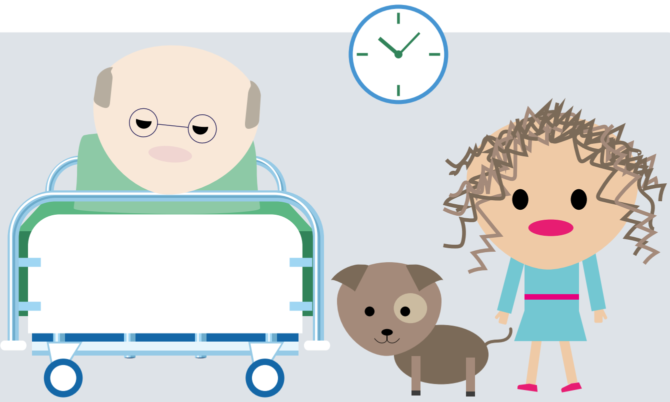
Chapter 3 Visiting your loved one in hospital

Patients can feel lonely and worried when they are in hospital so visiting regularly can help keep them in the loop and maintain their wellbeing while they are here with us. You may find it difficult at first to visit your loved one in hospital, but here are some top tips to make visiting easier:



John's Campaign



At the Royal Free London, we are proud to have pledged our support to John's Campaign – the right for carers of people with dementia to be welcomed onto wards outside visiting hours – across all of our in-patient wards.

Our ward teams are keen to meet with you and discuss plans to help support you and your loved one during their stay. Where possible, you will be able to stay with your loved one overnight. Sometimes this might not be possible, for example if we are obliged to provide single gender accommodation. We will be flexible with your needs and the needs of the other patients and hope that you can be flexible too.

Although we encourage you to help your loved one feel at home on the ward, please be aware that the hospital is a busy clinical environment and we have the duty of care for the patient and are ultimately responsible for the delivery of care.

Staying calm

It's easy to say, but it's really important that you try to keep calm while your loved one is in hospital. Not only will this make your life easier, but it will also help your interactions with the person with dementia.

People with dementia can be astute at interpreting and responding to body language, so if you visit them when stressed, angry or upset, this will likely be picked up by them. This can have a negative effect on the person with dementia as they are likely to already be feeling vulnerable and nervous and will be looking to you for reassurance and positivity. Leaving the ward to clear your head or restricting how long you spend on the ward in times of high tension can be useful coping strategies.

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What to talk about

It is very common for people with dementia to appear significantly more confused when they are in hospital compared to how they usually are at home. This can happen for lots of reasons ranging from delirium to changes in medication to just being in an unfamiliar environment.

Being prepared for unusual conversations allows you to give the person with dementia the reassurance that they are looking for and avoids the risk of arguing about the person's current version of reality.

- **Reassure** – it's a real skill to know when you should go along with something and when you should correct and that skill gets more precise with practise. If a person with dementia tells you that they came into hospital this morning there may not be much to be gained from saying, "well actually you've been here for 6 days". If however, they tell you that they are in their own home and they seem really frightened that the staff and patients around them have somehow got into their property, that might be an opportunity to say, "we're in hospital now, you've been here for the past couple of days". If they disagree with you and say, "no I AM at home" then maybe start a new conversation about home. You might say something like, "remember when you first moved in, we were so young weren't we?" Try to remember that they most likely value feeling reassured and safe over being factually correct.
- **Acknowledge their emotions** – sometimes patients with dementia internalise their anxiety and fear during the day and when a family member visits it gives the patient a chance to get it all out. Unfortunately, this can mean that anger and frustration can end up being directed at you when you visit which can often feel really unfair. Try to allow them that outlet without taking it personally.
- **Stick to familiar topics** – in hospital, a person with dementia is often bombarded with questions that they cannot answer. Talking about familiar topics and happy memories from the past helps them to feel more in control and connected to themselves. You may have heard these stories hundreds of times, but the pleasure and the benefit is in the telling.
- **Use props** – if all else fails, don't be afraid to use props to spark conversation or capture attention. Bringing in a newspaper or magazine can trigger a familiar routine and give you plenty to talk about, even if you're only looking at the pictures. If that's too much, reading to the person can still create a special moment between you. Photographs are another great way to help the person feel connected and talk about themselves and their life. Remember that the emphasis here isn't on you providing entertainment but on finding the right vehicle or topic for them to find self-expression. Sometimes just sitting quietly beside the person as they nap is enough.

Make a rota

If the person with dementia has other family or friends, it can be useful to agree an informal rota of visits so that when other people are going to visit, you can have a day off. If there is nobody else to share visiting responsibilities with, consider talking to the ward about whether they have a volunteer visiting service. If they do, this person could offer some companionship and conversation to your loved one to take some of the pressure off of you.

Chapter 4 Delirium

What is delirium?

Delirium is a term we use to describe a sudden onset of confusion. Delirium is very common with 15% of people (15 patients in 100) in hospital experiencing it at any one time. Having dementia increases the likelihood of developing delirium, but this condition can affect anybody, regardless of age or medical history.

Delirium can often be overlooked when a person has dementia because our hospital team may not know what level of confusion is normal for them. For a person with dementia, it can take longer for the delirium to resolve. It is really important that they have clear and accurate information from you so that they can identify and investigate any sudden changes in behaviour or memory that may indicate underlying delirium.

What does delirium look like?

There are 2 types of delirium: 'hyperactive delirium' and 'hypoactive delirium'. A person may have either hypo or hyperactive delirium or they may have a combination of both.

1. Hyperactive delirium

The person may appear more agitated or emotional. Their memory may be worse than usual and their speech may seem muddled. With this type of delirium, the person can often seem frightened or angry and may experience hallucinations or hold paranoid or persecutory beliefs (for example that they are in prison or that somebody is poisoning their food). In hyperactive delirium, a person may appear to have endless amounts of energy and may need very little or no sleep..

2. Hypoactive delirium

The person may appear more lethargic or withdrawn than usual. They may find it difficult to concentrate or focus on the thread of conversation when they are talking or when you are talking to them. With this type of delirium, a person can often seem very withdrawn or depressed. In hypoactive delirium, a person may appear to have no energy and may spend most of the day and night sleeping. Although this type of delirium is much more common, it is also harder to spot.

Common causes of delirium include;

- an acute infection (commonly urine or chest infection)
- constipation
- pain
- post-surgery
- medication
- dehydration
- change in environment

What can you do to help?

It's really important to identify what has caused the delirium so that the underlying cause can then be treated. For example, a person may have a urine infection that has caused a delirium. The delirium will not improve until the infection has been treated with antibiotics.

You can help us in the following ways:

1. Speak to us

If your loved one suddenly seems more confused, paranoid or lethargic while in hospital, ensure that the doctors and nurses are aware of this. This will prompt them to "Think Delirium" and investigate whether there is an underlying cause. The quicker they have this information, the quicker the delirium can be addressed.

2. Understand

It can be scary and upsetting to see a dramatic change in how a person thinks or behaves. Delirium can cause a person to behave in a very challenging way that is out of character for them. Keep in mind that they are acutely unwell and that given the right treatment this should significantly improve.

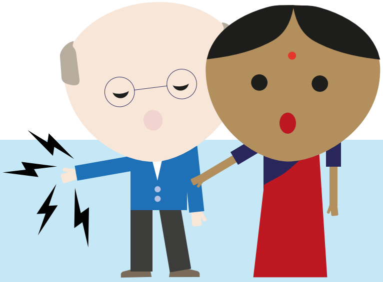
3. Visit

It is tempting to tell family or friends not to visit when a person is delirious. You may feel as though you make things worse when you're there or it may feel uncomfortable and distressing to see somebody experience delirium. Generally speaking, having familiar people visit and spend time with the person helps them to feel safe and less anxious in an unfamiliar environment like a hospital.

4. Reassure

People with delirium often fluctuate between moments of lucidity (clarity) and confusion. Vivid dreams and strange ideas can sometimes make a person feel that they are going mad. Reassure the person that they are safe. Remind them of where they are, why they are there and that they are a bit mixed up at the moment.

Chapter 5 Pain



Pain in hospital

Pain in people living with dementia is often an under-reported and under-treated problem in hospital. Untreated pain may be missed by staff because patients are not able to describe or report their pain in the same way that someone without dementia would.

Pain is a leading cause of delirium and is thought to be responsible for a large proportion of ‘distressed behaviours’ (see chapter 7). It can also change the way that a person communicates, interacts and participates in life on the ward which can impact their recovery.

Why does this happen?

As a person’s dementia progresses, they may lose some of the skills they relied on to identify and report pain. Changes to their memory, communication skills, and problem-solving may make it less likely that they can understand what their pain is and formulate a plan to have the pain treated. This means that often, people with dementia have to rely on the expertise of those around them to be able to spot that they are in pain and provide the appropriate treatment. Unfortunately, lots of the changes pain can cause in a person resemble some of the symptoms of dementia.

In order for nurses to administer pain relief to a patient, these drugs have to have been prescribed by the doctors on the ward. It is very common for patients with dementia to be written up for pain relief as “PRN” (pro re nata) or “on request”. This type of pain management plan makes doctors feel that they have prescribed the right pain relief, however, because it relies on the patient asking for pain relief it is often not an appropriate strategy for those with dementia as they lose the ability to recognise pain and ask for pain relief.

How to spot pain in somebody with dementia

When trying to detect pain in a person with dementia it is often useful to look out for non-verbal signs. This means that if a person experiences pain but has lost the ability to tell you, they are still able to have their pain managed in an efficient and appropriate way. As the person who knows your loved one best, you are in a really useful position to be able to spot whether there are any changes to the way a person seems to be or is behaving.

Signs to look out for include;

Sounds

Although a person may not be able to directly tell you that they are experiencing pain, they may make some sounds and noises that suggest that pain is present. Examples include crying, shouting, screaming, sighing, shallow or laboured breathing or any other sound that is unusual for them. They may be speaking at a volume or pace that is unusual for them or they may appear more repetitive or muddled than usual.

Facial expression

Knowing how your loved one looks when they are relaxed makes it much easier for you to be able to spot when they look tense, uncomfortable or in pain. There are some common things to look out for. These include frowning, a furrowed brow, tense jaw, downturned mouth or grimace.

Body language

The presence of pain may cause a person's body language to change. The person may cradle or nurse a part of their body or they may attempt to guard or protect a part of their body. You may notice changes in the way a person sits, walks or holds themselves. They may appear more rigid and tense or they may develop a repetitive movement pattern, for example, tapping the hands or fiddling with buttons.

Behavioural changes

Changes in behaviour, routine and the way that a person interacts with others can all be signs of untreated pain. A person who is usually relaxed and chatty may suddenly appear irritable and distant or somebody who is usually very active may want to stay in bed all day. Pain can cause people to lose interest in food and some may have difficulty sleeping. Pain is also responsible for some of the 'distressed behaviours' people with dementia can experience, for example, aggression, swearing and agitation. It is important to remember that these behaviours are usually caused by underlying problems, untreated pain being a very common one.

Pain causing conditions

As most people get older, they develop a number of long-term conditions of which dementia may be one. It's important to remember that a person's other conditions still need to be treated and managed, as many of these conditions cause pain. Arthritic diseases, as well as age-related damage to joints, bones and muscle can cause general aches and pains as well as more acute pain.

There are also likely to be instances where pain is present for reasons that are not immediately obvious. For example, if a person has had a fall, they are likely to experience pain even if they have no visible injuries. Similarly, if a person is usually very active and they are now spending a lot of time in bed or sitting down, this can also cause significant musculoskeletal pain.

Oral and gum pain is common in people with dementia. If your loved one has lost weight, or if they have not been brushing their teeth regularly whilst in hospital, denture pain, cavities and other problems in the mouth can be very uncomfortable.

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What if I spot any of the above signs?

Report it

If you see one or more of the above non-verbal indicators of pain, it's really important that you are able to share that information with us. It's important that you take note of what signs are present so you will know what to look out for in the future. Similarly, we can learn these signals and may be better at spotting pain in the future.

Discuss treatment plan

Once the presence of pain is established, it is important to discuss pain management options with the medical team caring for the patient. Many people find that administering a painkiller regularly on a four-hourly basis is the best way of keeping on top of pain. The team will be able to advise you on what the right choice for pain relief is, mindfully avoiding medication that may make the person feel more confused or become constipated.

For people with dementia who do not like taking pills or who take them irregularly, it may make sense to think about a different way of getting pain relief to them. In cases like this we have found that a pain relieving patch (where the medicine is slowly released through the skin over a steady period of time) can deliver good pain relief in a minimally intrusive way.

Calm and distract

Studies have shown that the subjective experience of pain is worse for people who are lonely, bored or worried. This means that once an appropriate pain management plan is in place, there are lots of other things that you can do for the person to make their experience of the pain improve. Regular visits, meaningful activities and chats about familiar topics can help distract a person from any unpleasant feelings or sensations. If your loved one is spending more time in bed or a chair than usual, you may be able to ask the ward physiotherapist whether they can prescribe any gentle exercises for them which you can practice together.

Chapter 6 Mobility

What we mean by mobility

Mobility refers to the way a person is able to move around, usually by walking. It can also describe a person's ability to use a wheelchair or other assistive equipment. A key part of mobility is what we call 'transfers'. This refers to the process by which we move from one position into another, for example, from laying to sitting or from sitting to standing. Mobility is a key component of how the team will assess your loved one's independence and progress in hospital.

Mobility in hospital

It is very common for a person with dementia to experience problems with their mobility as a result of illness or accident. People who are unwell are less likely to be active and, for people over the age of 80, 10 days in bed can age muscles by 10 years. Inactivity in hospital can also contribute towards other health problems such as pressure sores, circulation and breathing problems.

Hospital environments themselves can cause additional difficulties for people living with dementia and these patients are often at the highest risk of hospital related deterioration or 'deconditioning syndrome' as it is sometimes known. The noise, layout and signage on hospital wards can cause a person to become more reliant on help when completing daily activities such as using the toilet, washing and dressing.

The good news is that there is an increasing awareness around the consequences of inactivity among older patients and we are running several initiatives at our hospitals to change this and help patients to mobilise. Here are some tips and advice on how you can help.

Work with the right professionals

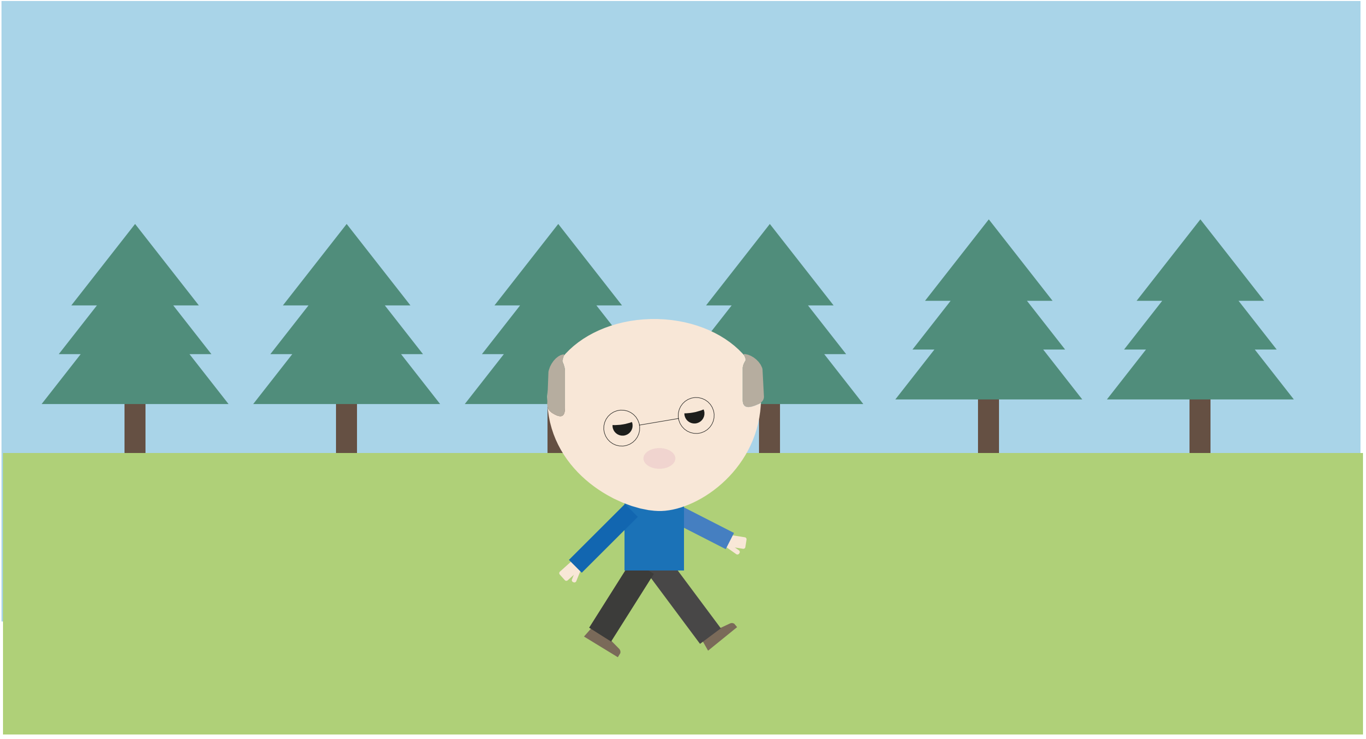
A number of professionals are likely to be involved with assessing and practising your loved one's mobility; physiotherapists, occupational therapists, nurses and nursing assistants to name a few. Your involvement, information and support at an early stage can help them use the right information to make the best clinical decisions. Helping the team understand what level of mobility is normal for them and what equipment and techniques they are used to. For example a person may use a raised toilet seat to help them stand up from the toilet or they may 'furniture walk', which is a technique where people walk around a space using furniture to support them.

The right equipment

The physiotherapist may have prescribed a piece of equipment, for example a Zimmer frame or crutches, for the person to use to promote independence and safety. It's important that you understand how it should be used so that you can encourage the person you care for to use it when walking. In addition to prescribed equipment, there are items that you can bring in to improve a person's ability to mobilise independently; well-fitting slippers or trainers, glasses and hearing aids. Most of our wards like to encourage patients to wear their own clothes so please bring in warm, breathable and non-restrictive garments for your loved one to wear.

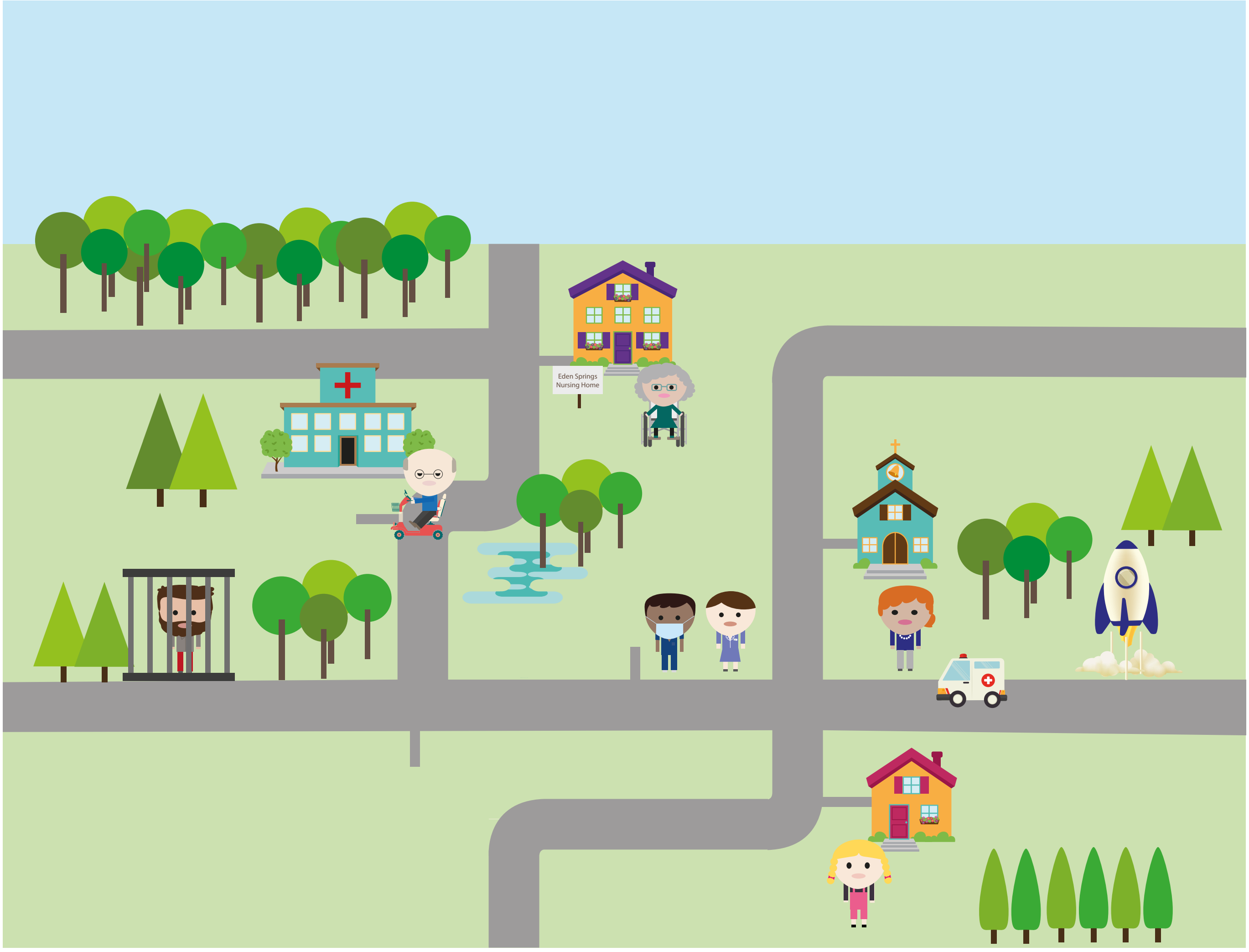
Help make walking a part of the normal daily routine

Walking should be a regular part of life on the ward and should be a normal part of completing other tasks if appropriate. The best strengthening exercises are performed as part of a person's usual daily tasks. For example, standing at the sink to brush their teeth or walking to the bathroom to use the toilet rather than having a commode wheeled to their bedside. Being up and mobile has a number of positive effects such as helping build appetite and reducing the risk of constipation. If your loved one is unable to walk, ensuring that that they are sitting out in a chair rather than lying in bed where possible can still be of benefit.



Help keep the person active and engaged

When a person with dementia is in hospital and is anxious and frightened by their new surroundings and routine, it can sometimes be hard for the staff to successfully engage them in an activity such as walking. You can be really useful in helping staff to understand the best way to explain things to the patient, what the best way to motivate them is and what time of day they might feel more inclined to get up and walk. Sharing information about the person’s interests, routine and personality can help the staff build a relationship with them that can improve how they work together.

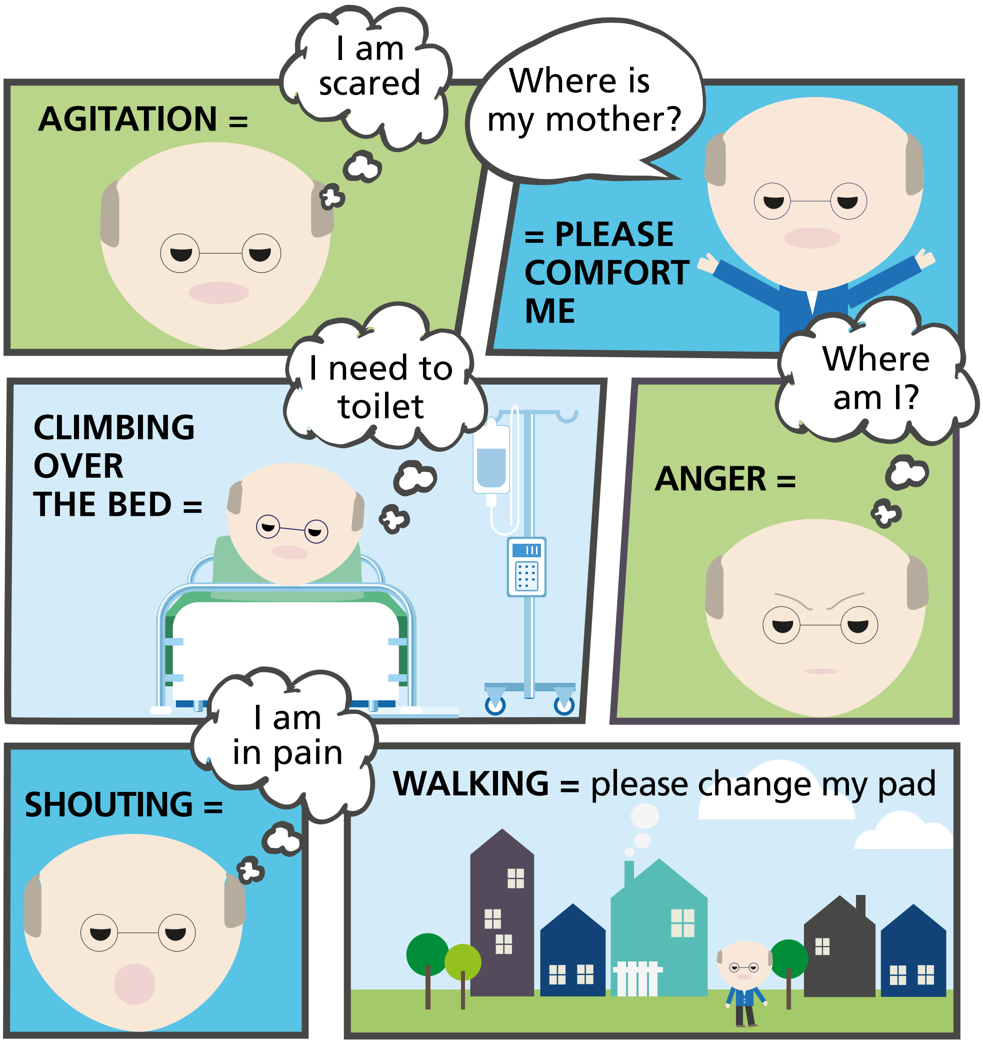


Chapter 7 Distressed behaviours

What is distressed behaviour?

Distressed behaviour describes emotions and actions that cause the person with dementia to experience discomfort or distress. Examples include:;

- shouting
- agitation
- aggression
- paranoia
- anxiety
- repetitive questions
- wandering
- sadness/ tearfulness



Being admitted to a hospital, away from your familiar surroundings and support network, can be confusing and distressing. Dementia impacts a person's ability to adapt to new situations so patients can feel overwhelmed by and become frightened and agitated.

Changes to behaviour, especially those that seem out of character, can be extremely difficult for relatives, friends and carers to manage. This is sometimes referred to as 'challenging behaviour', but this can incorrectly imply that the things people with dementia do and say are a 'problem'. It's much more helpful to think of these behaviours as a way of communicating distress. This should prompt us to try to understand the meaning behind the behaviour and find out how best to help.

What causes distressed behaviour?

Dementia changes a person's ability to communicate as well as their ability to think things through and problem-solve. This causes a great deal of frustration and stress for them and those around them. Behaviour such as anger and agitation is the result of the person with dementia feeling misunderstood or unheard.

Having dementia can affect a person's ability to think of coping strategies and have the ability to carry them out. For example, how can somebody relieve their pain if they can't work out what this horrible sensation that they are feeling means? How can they talk through their worries with a loved one if they can no longer articulate how they are feeling?

Without their usual coping strategies, people with dementia search for alternative forms of expression. Common messages hidden within distressed behaviour include:

Pain – research shows that people living with dementia are less likely to be offered or receive adequate pain relief. This might be because they find it difficult to recognise pain, locate where it is and report it to a doctor or loved one.

Delirium – this is a sudden state of increased confusion usually caused by an underlying factor such as infection, pain, constipation or dehydration. Understanding and recognising when a person is showing signs of delirium can help ensure that underlying causes are identified and treated (see chapter 4 for more information).

Boredom – the way that we care for people living with dementia can sometimes mean we need to remove or restrict their roles and responsibilities. This can cause boredom, which can lead to frustration, irritability, depression and agitation.

Depression and anxiety – these conditions are significantly more common amongst people with dementia and are often overlooked because the symptoms can be mistaken for dementia. Distressing behaviours could include disturbed sleep, reduced concentration, agitation, restlessness and wandering.

Versions of reality – you may find yourself in an uncomfortable situation when a person with dementia talks about things that you know are factually incorrect. A bit of detective work can help you to sift out the meaning. For example, if somebody talks a lot about needing to go to work or pick up their children from nursery, you could interpret that those roles (employee, mother) brought meaning into their life. You could talk to them about these roles, listen to their stories and think about how you can create a meaningful role in their life now. This could include supporting them to do chores or parts of their daily routine.

How can I manage this?

The most important thing is to not take difficult behaviour at face value. Like everyone, people with dementia do and say things for a reason that is meaningful to them. What may appear irrational or illogical to us makes sense to them and it is our job to try to work out the message hidden in the behaviour. To be able to communicate efficiently with the person, we have to learn to speak the language of dementia. We need to watch what the person is doing, not just what they are saying and repeatedly ask yourself the question, "She seems angry; what is she trying to tell me?".

Keep a behaviour diary

Keeping a record of what a person does and when can give you an idea of what their message might be. For example, if the person becomes frightened and tearful four times a day, try to take note of the time to help work out what the underlying need is.

A behavioural diary may help you to identify triggers or causes of distressed behaviour. During or after an incident it may be helpful to ask yourself the following questions:

- What time of day did this happen?
- Who was present?
- What room were we in?
- What were we doing?
- What did the person say?
- What was their behaviour like?
- Did anything seem to make things calmer?
- Did anything seem to make things worse?
- How long did it last for?
- Could they remember the incident afterwards and if so could they tell you what happened?

Once you identify a trigger, you are able to think of ways to either remove the trigger or, if this is not possible, add extra support for the person at times when they are likely to be triggered.

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Let the team know

For carers, seeing distressed behaviours in the hospital can cause a great deal of stress, worry and upset. It's important for you to let our hospital teams know about any new behaviour that you observe because this might be an indication of an underlying, treatable problem such as a delirium or pain.

Communication

We know that a person's ability to communicate is affected by their dementia, but we also need to think about the way in which their dementia should change our communication too.

Here are some key tips to consider when communicating:

- Look at the person when you are talking to them
- Minimise any environmental distractions, for example, turn the TV down or off and make sure that you have their full attention
- Speak slowly and get straight to the point
- Pause in between sentences to ensure that they have understood you
- Repeat yourself as often as necessary
- People with dementia often lose the ability to communicate verbally, but retain the ability to communicate non-verbally, souse other forms of communication such as gestures, facial expressions and the tone of your voice
- If somebody is shouting and distressed, try to use a low, soothing tone to your voice. If you match their energy you will likely escalate how they are feeling
- If you are feeling impatient or stressed out, the person with dementia is likely to pick that up and react to it. Make sure you give yourself a moment to clear your head and keep your composure

Reassurance

Kindness, patience and an understanding of the reality are key to helping the person living with dementia feel safe and understood. Don't underestimate the power of a kind gesture such as a hold of the hand, a cuddle or a cup of tea.

Chapter 8 Discharge

As soon as your loved one is medically stable, the team caring for them will start making plans to discharge them home as soon as possible. With the right support, most people with dementia do better in a familiar environment.

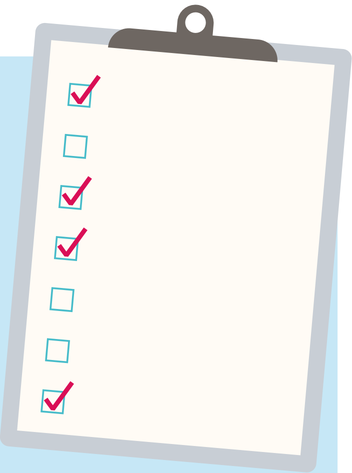
If they are being discharged somewhere other than their usual place of residence, either temporarily (for example, to a rehabilitation facility) or permanently (for example, into a nursing or residential home), a series of assessments and conversations need to take place with you and the person with dementia in advance.

It's really important that you are involved in these discussions and that you feel happy with, and understand the discharge plans and have had the opportunity to have your own concerns heard and needs assessed.

Assessments prior to discharge

Once the person is medically stable, the MDT will carry out a series of assessments on the ward. The assessments will depend on individual need but may include:

- Physiotherapy assessment of mobility
- Occupational therapy assessment of ability to perform their usual daily tasks and participate in a meaningful routine of their choosing. This may also include an assessment of the person's home environment
- Speech and language therapy assessment to determine whether communication or swallowing guidance may help the person
- Dietitian assessment to help optimise the amount of nutrition and calories the person is consuming.
- Social services assessment to determine whether or not your loved one requires a temporary or longer-term package of care. A package of care is a support plan designed by social services whereby a care worker visits your loved one's house to support them with any activities they need support with. Packages of care are designed around the specific needs of the individual and therefore the level of support varies from case to case. The support that is provided may be free or it may be means tested (meaning that the person with dementia may be asked to make a financial contribution towards their care) depending upon the individual circumstances and the council providing the care.
- Social services should also assess your needs as a carer. This may be done while the person with dementia is in hospital or it may happen soon after they have been discharged home. The carer's assessment should cover the following areas; your



caring role and what is involved, your health, your well-being, stress levels and any worries you might have as well as how your caring role impacts other parts of your life including work, relationships and hobbies.

- If the person with dementia is not returning to their home and they require a nursing or residential home, then a different set of assessments need to take place. Usually part of the NHS Continuing Healthcare system, these assess whether the person's primary need for a move to this type of facility relates to their physical health (requiring care provided by a registered nurse) or whether the care falls under social care (requiring care provided by a care assistant).

Getting involved early

Good communication between the hospital team, the person with dementia and you is essential to making the right decisions around discharge and ensuring that everybody feels supported and comfortable.

Here are some tips for encouraging early involvement in discharge planning;

- Introduce yourself to the ward team and ask to be involved in discussions around discharge. The ward who team can tell you who is taking a lead on planning the discharge for your loved one and can advise on who is the best person for you to liaise with.
- Keep up to date with what is happening. Lots of factors are involved in planning a discharge and sometimes plans do change or need to be modified at short notice. To ensure that you are up to date, check in regularly ward sister or the person who is leading the discharge.
- If there is more than one person involved in caring for the person with dementia, it is often a good idea to decide on one spokesperson or single point of contact – this can help facilitate better communication.
- Understand the decision-making process. When a person with dementia is admitted into hospital, there is a legal presumption that they are able to make decisions for themselves under the Mental Capacity Act 2005. If the team looking after the person with dementia have reason to believe that they are not able to make a specific decision for themselves they will carry out a mental capacity assessment. It asks whether or not they are able to understand, retain, weigh and communicate information pertinent to a specific decision. If they are found to have the capacity to make decisions then they will be left to make the decision in question for themselves. If they are found to lack capacity, a decision will be made on their behalf either by an appointed Power of Attorney (LPA), an Independent Mental Capacity Advisor (IMCA), family/ carer and the treating team involved in their care. The decision reached must be in the person's best interests and should take into account any previous wishes or opinions the person with dementia had prior to losing capacity.

Practical considerations prior to day of discharge

- If medication has changed, make sure you know the new schedule. If the change is something that the person will need support in keeping up with their GP or our hospital pharmacists may be able to provide them with a dossette box, or they can be purchased privately.
- Make sure the person has a weather appropriate outfit for the day of discharge.
- If the person's medical treatment is finished then they will likely be discharged back into the care of their GP. They will receive a letter from us detailing the events, diagnoses and treatment during the admission. If the person has had an operation or procedure they may be required to attend a follow-up appointment in the weeks or months post-discharge. Find out as much as you can about this, including when and where the follow-up appointment letter will be sent.
- In the days leading up to discharge, take the names and numbers of those involved in the discharge. This can give peace of mind in the days following a discharge home.
- Even if the person is usually able to do some shopping themselves or go with you to the supermarket, it can be a good idea to make sure that there are enough fresh groceries in to last a few days.

Practical considerations on the day of discharge

- Morning discharges are usually best for a person living with dementia. Morning discharges give you plenty of time to get the person home and settled in before nightfall. If a morning discharge is to be successful, everything should have been fully confirmed and completed the day before discharge
- Transport is a key consideration of the discharge process. You will want to know how the person is getting home and what logistics are involved. We may move your loved one from the hospital ward to our discharge lounge to wait for transport. Usually, hospital transport is not a direct journey from the hospital to the person's home and often, patients are transported in small groups in an ambulance. For people living with dementia, this is not ideal. Speak to the ward sister about whether or not you would be able to travel home on the ambulance with them or, if the person is mobile, you may be able to take them home yourself in a car or taxi.
- Make sure that the ward has a copy of the person's house keys so that they are able to get in once they arrive. If you have not been able to travel in the ambulance with them, it is sometimes a good idea to be at home waiting for them so that you can let them in and start to settle them straight away.

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Settling in at home

It is likely that the person living with dementia will require some time and support to settle back into their home environment and daily routine. It is usually easier to settle somebody back into home than it is to settle them into hospital but the same principles apply. Reassurance, a calm and relaxed environment and quiet time can help the person feel safe and happy to be home.

If the person has been delirious or if they have had a change in their functional abilities as a result of their time in hospital, they may need some time to adapt to new circumstances. If the person is having a new package of care, it is often useful to be there the first time the new carer visits. This gives you the opportunity to meet the person and properly introduce them to your loved one.

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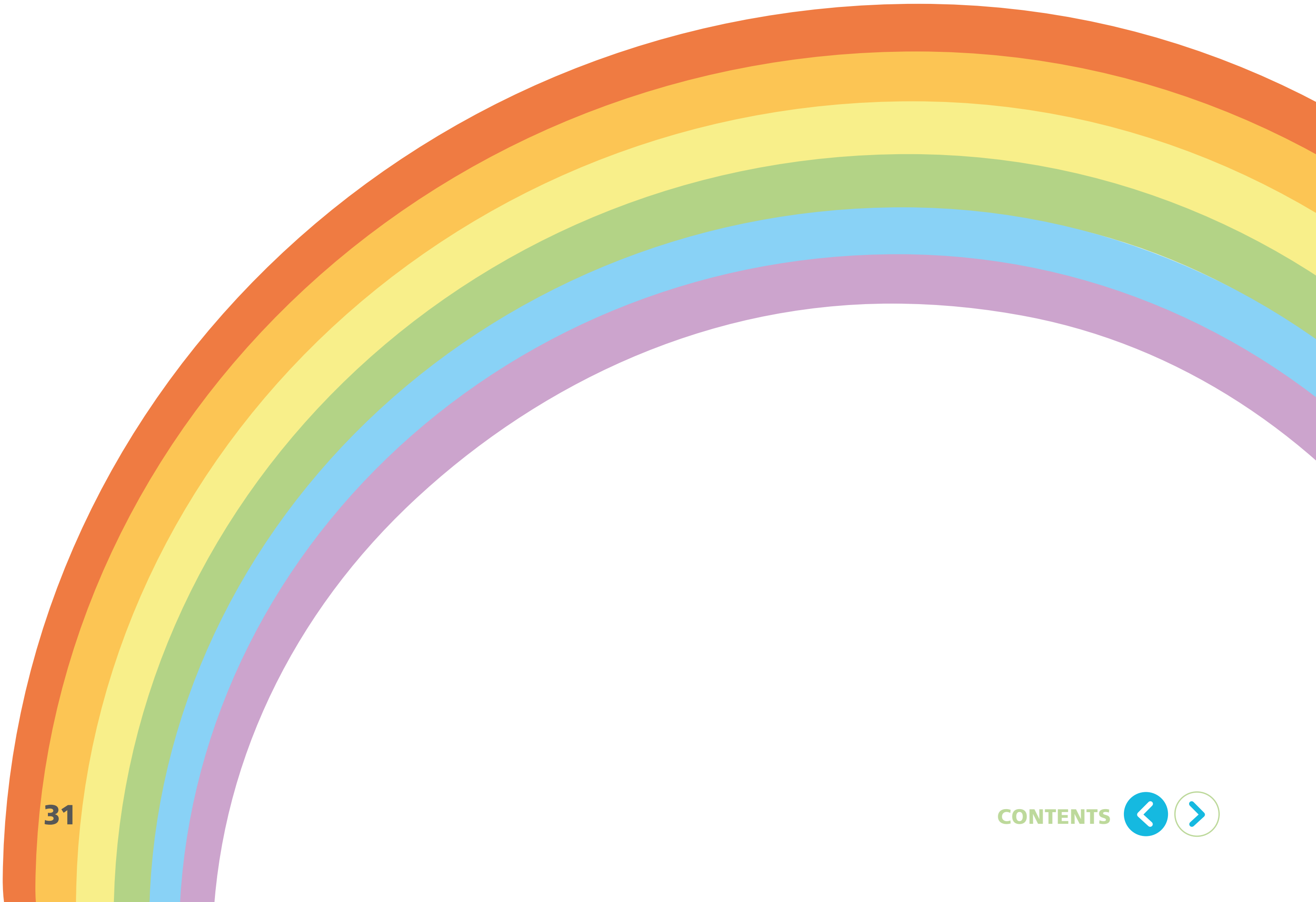
End of life care

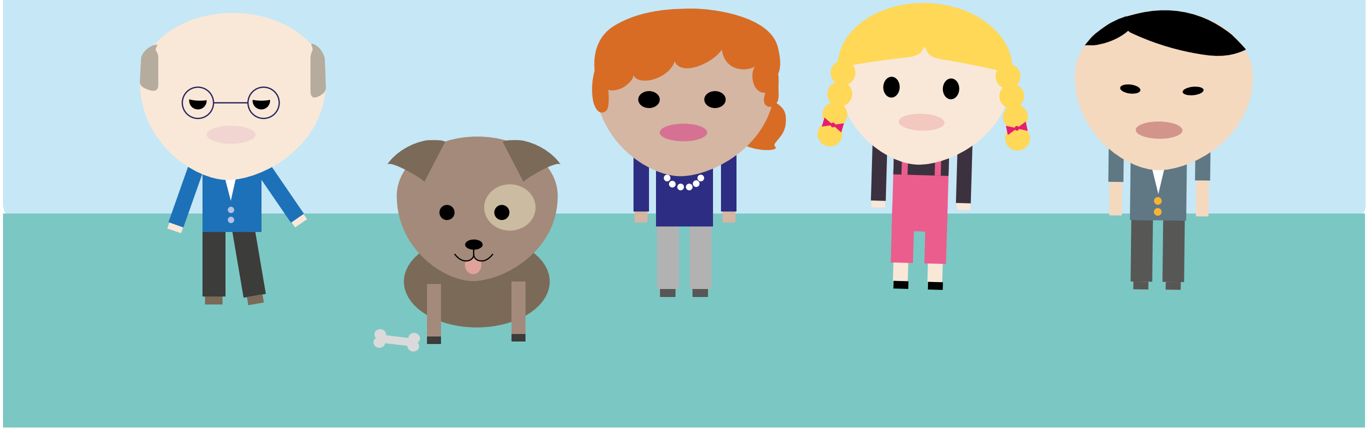
If a person with dementia is approaching the end of their life then it is not always appropriate to start discharge planning. End of life discussions and decisions are complex and upsetting for family and carers and our specialist palliative care teams can help navigate these difficult circumstances.

If the person is too ill to leave hospital then it may be possible to make arrangements with the ward about making their remaining time in hospital more comfortable. If the person has previously expressed wishes about where they would like to die, our teams will work hard to honour this where possible. A person may be supported home or they may be moved into a hospice. Our specially trained nurses and chaplains will be on hand to offer the support that you need through this difficult time.



Chapter 9 Support in the community for people with dementia

People with dementia sometimes report feelings of isolation and loneliness living with the diagnosis. Even those who are lucky enough to have friends and relatives close to them have to renegotiate their relationship with themselves and the world around them. Luckily, there are many pockets of support around for people to tap into as they wish.



Healthcare professionals

GPs should be the first line of support with the everyday issues relating to a person's health and wellbeing. Some people avoid seeking help from doctors, but the fact is that the better the GP knows the person with dementia, the more information they will have about them and the better quality of care they will be able to offer. A GP should review the health needs of a person with dementia at least once a year and monitor the progression of their dementia. The GP is also able to refer people with dementia on to specialist services as and when required. Some services they can access include:

- Psychologists and mental health specialists
- Specialist dementia nursing services
- Physiotherapists
- Occupational therapists
- Audiologists
- Dietitians
- Speech and language therapists

Memory clinic

The majority of people with symptoms of dementia are assessed and diagnosed through a memory service, usually accessed through a GP referral. Memory clinics usually have a number of different healthcare professionals working together as a team and can include psychiatrists, therapists, nurses and social workers. As well as diagnosing dementia, memory clinics are often involved in monitoring people with a diagnosis of dementia and can offer specialist advice and interventions when a person's dementia changes; for example when distressed behaviours or increased care needs become a feature.

Social services

A social worker can be accessed through your local council and they can be an important source of support. Social workers can assess a person to determine whether support at home from care workers could keep people in their own homes for longer and keep them safe and supported. These services will be means tested and there will be a charge for some people.

Social workers can also provide advice regarding further support services available in the community, for example advocacy services, and can also make referrals for people to attend community organisations such as day centres and activity groups. They can support with finances and ensure that a person is receiving all the benefits that they are entitled to.

Charity and not for profit organisations

Charities and not for profit organisations provide key support and services in local communities for people living with dementia and those close to them. Directly contacting organisations such as Age UK, Dementia UK and the Alzheimer's Society is a good first step to finding out what is available in your local area. For those people who are able to use the internet, the Alzheimer's Society also has a useful tool on their website called "Dementia Connect" where it is possible to search for resources by postcode.

Services that may be available in your area include;

- **Peer support services** where people living with dementia meet regularly to support each other and share experiences.
- **Dementia advisers** are community based support workers who provide a free service to people living with dementia and their friends and family. Dementia advisers can tell you exactly what services are available in your area and signpost people to additional support.
- **Dementia cafes** are local coffee and tea mornings – often held in community centres – specifically geared towards people living with dementia and their carers. These social groups are designed to be supportive safe spaces for people who may feel nervous or overwhelmed by the prospect of socialising.
- **Activity groups** such as 'singing for the brain' choirs, walking groups or art groups can give a person with dementia something to look forward to each week and a sense of purpose. Staying connected to community and to the activities that have always been meaningful to a person is an important way of creating well-being and fulfilment in a person with dementia.
- **Handymen schemes** are available in some areas and provide trusted and reasonably priced (sometimes free) services to people living with dementia. They can be asked to help with small jobs around the home such as changing light bulbs or can support with larger repair works.
- **Admiral nurse**s are specialist nurses available in some areas provided by Dementia UK. These nurses support people with dementia as well as their families.
- **Advocacy services** can help people sort out their finances and some legal matters. As well as providing free advice around money management and debt, they are also able to ensure that the person living with dementia receives all of the benefits they are entitled to. Some advocacy services are able to support with will-writing and decisions relating to appointing powers of attorney.

Useful numbers

Age UK	Phone: **0800 169 2081**	Website: **www.ageuk.org.uk**
Alzheimer's Society	Phone: **0300 222 11 22**	Website: **www.alzheimers.org.uk**
Dementia UK	Phone: **0800 888 6678**	Website: **www.dementiauk.org**

Chapter 10 Caring for yourself

Caring for yourself

Carers are an enormous help to us. You are the person who knows your loved one best and your experience, knowledge and participation is a crucial part of delivering good treatment and planning safe discharge for the person with dementia.

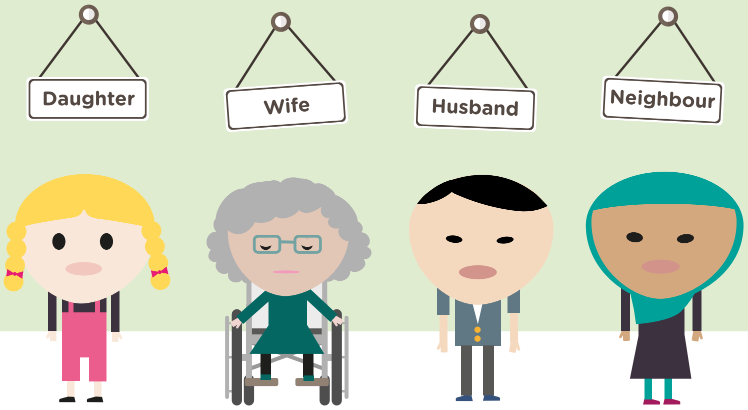
Although it will be a difficult time for your loved one, it can also be a very challenging time for family and carers of the person, so we encourage you to look after your own health and wellbeing and talk to us or others in the community about any concerns or support you need.

Support in the community for you

Many people who care for those living with dementia don't even consider themselves to be carers. They think of themselves as spouses, children or friends of the person with the diagnosis, so they might not acknowledge the extent of the support that they are offering and the impact it's having on them.

Caring for a person with dementia can be a stressful and complex job and being a carer can be a position that people find themselves in rather than one they've chosen. People often receive no training or support to do this role and as well as being concerned about the person with the diagnosis, carers may find themselves dealing with emotions like guilt, anger and resentment. Carers of people with dementia may experience higher levels of stress and are more likely to experience depression and anxiety than carers of other older people. The support a person with dementia needs is likely to more than the needs of another older person, so carers of people with dementia may be more likely to need to reduce hours or give up work and so may face financial challenges. They are also less likely to focus on their own health and well-being and can experience higher incidences of ill-health than people who aren't carers.

It's vital that carers of people with dementia find a way to prioritise their own health and well-being and actively seek support. This might be informal support from friends and family or formal guidance from health and social care professionals. In a complicated caring role, you may feel that finding time for yourself isn't a priority but looking after your own health and finances makes you far more able to care for your friend or relative.



Building a support network

Friends and family: having people around you that you can talk to might help you feel like you're not the only person in this situation. If you have a close friend you can talk to, let them support you by telling them about your caring responsibilities and how you're feeling. If you have family members around, let them know what you are doing and how you are feeling. They may be able to share some of your caring responsibilities so that the pressure isn't all on you.

Peer support: even if you have close friends and family, there may be some parts of the caring experience that you feel uncomfortable sharing with them. Sometimes you might feel angry or frustrated with the person you care for and this might make you feel guilty or self-blaming. You may worry that someone who hasn't experienced how it feels to be a carer might judge you. Sharing experiences with people who are also caring for friends or relatives is an important source of support for lots of carers. Most areas will have a carers centre associated with local social services that host regular meetings, activities and social events. If getting out to a physical meeting is difficult, most dementia support websites (see above) have active online communities that you can join and use 24 hours a day.

Talk to your GP: it's important to tell your GP that you are caring for somebody. They may be able to support you by referring you to other teams and you can ask them for help if things become difficult. GPs can access counselling and psychological services that many carers of people with dementia find useful. Seeking emotional or psychological support in your caring role doesn't mean that you're not coping. Professionals can teach strategies to help you cope with the difficult times, which not only improves your health and well-being but also your ability to carry out your caring role well.

Talk to social services: it's a good idea to involve social services when you start to care for a person with dementia. All carers are entitled to a care assessment in which the social worker assesses the practical, financial and emotional needs of a person providing care for a loved one or relative. They can refer you to support networks like carers centres and make sure that you are receiving all the benefits that you are entitled to. They may also provide or refer you to advocacy services which can help with matters like wills and power of attorney. Social services can assess whether any of their services can help you and the person you care for – for example if it's uncomfortable for you to provide intimate care to a parent, they may be able to provide a carer who can do that part of the caring role. Social workers can also help find respite care placements for the person you care for which may enable you to take a break or go on holiday. They are often a key support in a crisis situation or when your needs or the needs of the person you care for changes.

Memory clinics: most people with the symptoms of dementia will be diagnosed in a specialist memory clinic. Memory clinics consist of mental health doctors and nurses as well as social care professionals. If the person you care for wasn't diagnosed in a memory clinic, it may still be possible to be referred if the person's behaviour or mental health needs become difficult for you to manage. As well as having specialists to support the person with dementia, some memory clinics can offer support and advice to you as a loved one. Speak to your GP about which support is available from your local memory clinic.

Be realistic about what you can do

Dementia is a progressive, complex and incurable condition so if you find yourself in a situation you can't cope with, be kind to yourself and be realistic about what you can and can't control. Caring may sometimes feel overwhelming so it might be useful to make a list of all of your responsibilities. For example, if you need to work to pay your bills and your mortgage, it's important to recognise from the outset that you'll need to keep working. It's useful to know your limits so that you know when to ask for help when you need it.

Be kind to yourself

Most carers would rather put the needs of the person with dementia before their own but this isn't always the best idea. Looking after your own health and wellbeing is one of the most useful things you can do to support the person with dementia and sometimes that might mean taking some time off or away from the hospital.

Health: if the person you care for felt unwell or distressed, you would ask for help on their behalf. But evidence shows that carers of people with dementia aren't as diligent in looking after their own needs and may be more likely to suffer from mental and physical ill-health. Visit your doctor, eat well, exercise and get enough sleep.

Social: it's important to spend time with a mixture of people, who can all offer you support. Even if you don't feel like socialising, you might enjoy spending some time on your own.

Wellbeing: making time for yourself is essential, so remember to do the things that you enjoy or help you relax. Having a bath, reading a book or going for a walk may help. Leaving the person you care for to do something for yourself may feel strange, so it might help you to think of this time as an investment in your longer-term ability to care.

CONTENTS

Useful contacts

Age UK
Phone: 0800 169 2081
Website: www.ageuk.org.uk

Alzheimer's Society
Phone: 0300 222 11 22
Website: www.alzheimers.org.uk

Barnet Carers Centre
Phone: 020 8343 9698
Website: www.barnetcarers.org

Camden Carers Centre
Phone: 020 7428 8950/55
Website: www.camdencs.org.uk

Carers in Hertfordshire
Phone: 019 9258 6969
Website: www.carersinherts.org.uk

Dementia UK
Phone: 0800 888 6678
Website: www.dementiauk.org

Enfield Carers Centre
020 8366 3677
www.enfieldcarers.org

Royal Free Charity carer's support hub at the Royal Free Hospital
For all enquiries or to make an appointment:
Phone: 020 7794 0500 x 39963
Email: rf.royalfreesupporthub@nhs.net

Royal Free London NHS Foundation Trust key contacts

Chaplaincy

For more information about the chaplaincy service at the Royal Free London visit our website:
www.royalfree.nhs.uk/patients-visitors/advice-and-support/chaplaincy-multi-faith/

Dementia lead

Email: daniellewilde@nhs.net

Patient advice and liaison service (PALS)

Barnet Hospital: 020 8216 4924

Chase Farm Hospital: 020 8216 4924

Royal Free Hospital: 020 7472 6446/ 6447

For more information about the PALS team at the Royal Free London visit our website:
www.royalfree.nhs.uk/pals

If you have any feedback on this guide or for a list of references, please email: rf.communications@nhs.net

This leaflet is also available in large print. If you need this leaflet in another format – for example Braille, a language other than English or audio – please speak to a member of staff.

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