

Dementia :: Understanding & Living

Helping families better understand the dementia journey



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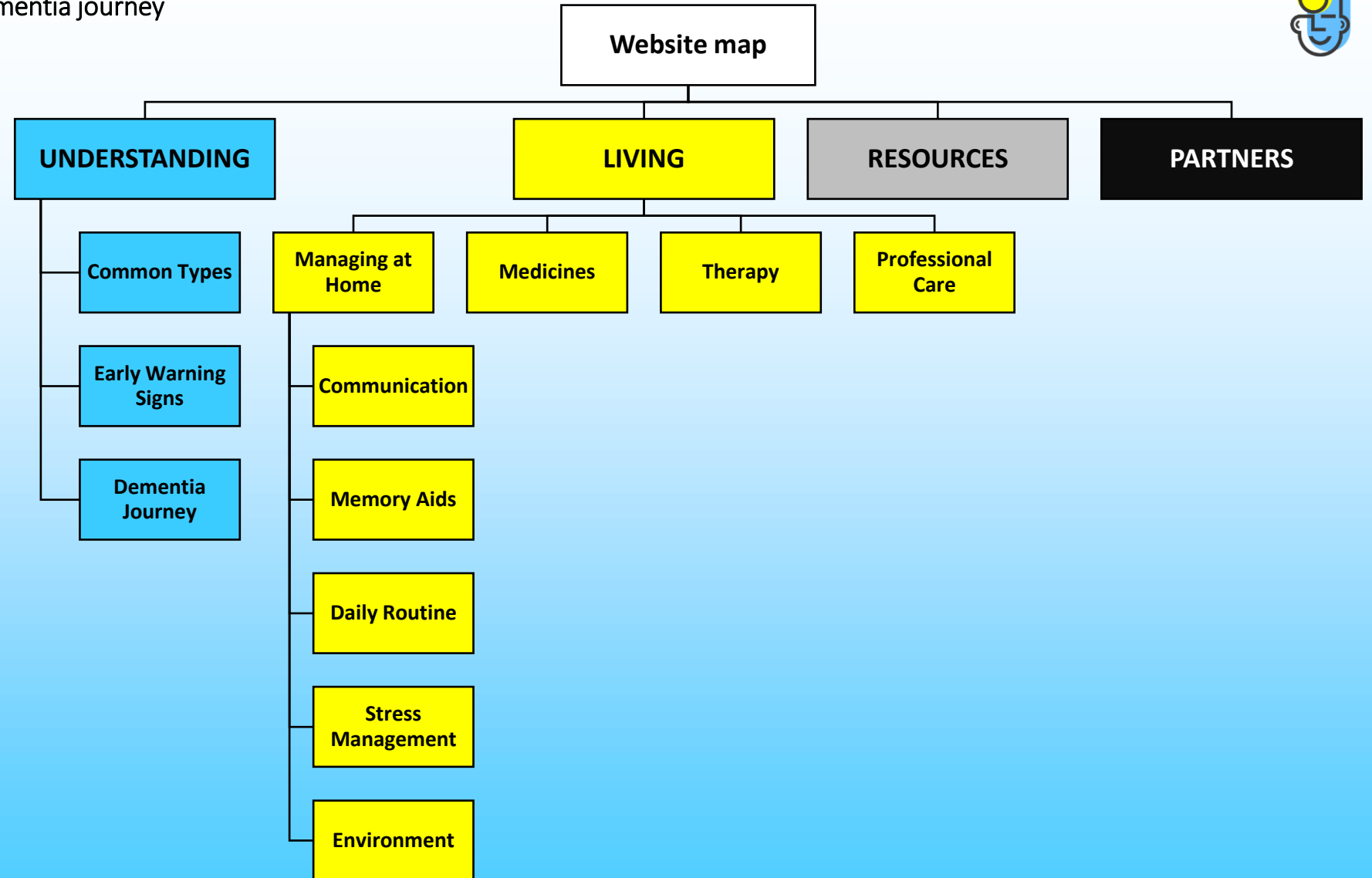


There is lots of great information on dementia available online and from your local health & medical centres.

However, it can often be overwhelming due to medical jargon and the sheer quantity of information.

The aim of this website is to help you gain a better **Understanding** of dementia and suggest practical solutions which may help sufferers and their carers when **Managing at Home**.

Disclaimer – This website has been created for general information purposes only and does not constitute professional advice. You should always seek advice from a health care or medical professional.



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UNDERSTANDING

What is Dementia?

Dementia is the umbrella term used to describe a range of conditions affecting the brain. It is most often associated with the impaired ability to **remember, think,** or **make decisions** that interferes with completing everyday tasks.

It is a disease of the brain, and it does not just affect older adults.

Dementia can arise from a wide range of conditions or illnesses. It may arise from a stroke or vascular disease, infection, fever, build-up of proteins on the brain, long term alcoholism, drug misuse, Vitamin B12 deficiency, head trauma, thyroid difficulties and tumours.

Whilst Alzheimer's Disease is the most prevalent form of dementia, there are several [common forms](#) of dementia.

Early Warning Signs

There can be some [tell tale signs](#) to look out for, which should not be confused with changes in the brain due to normal aging.

A standardised scale called the [Reisberg Global Deterioration Scale](#), categorise the symptoms into 7 stages.

The Dementia Journey

From early warning signs through to living in a professional care setting, the journey will vary for each person. Click on [dementia journey](#) to read more.

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UNDERSTANDING

Common Types

[Alzheimer’s Disease](#)

[Vascular Dementia](#)

[Dementia with Lewy Bodies](#)

[Frontotemporal](#)

[Huntington’s Disease](#)

[Young Onset Dementia](#)

[Korsakoffs Dementia](#)

[Sports Related Dementia](#)

[Parkinson’s Related Dementia](#)

Early Warning Signs

Not to be confused with simply getting older, understanding the difference between an aging brain and dementia can be relatively tricky.

Most adults will begin to experience some form of mild cognitive changes and memory loss as they grow older.

Early warning signs can be different for everyone depending on type of dementia and part of brain impacted.

The table to the right is a guide to help you distinguish between Old Age and Dementia.

Likely Old Age	Likely Dementia
Becoming less patient and less tolerant.	Significant change in personality and behaviour or inability to rationalise and reason.
Forgetting names of people or items they haven’t seen or spoken about in years.	Forgetting names of people or items they see and interact with on a regular basis.
Forgetting someone’s birthday or the reason you entered a particular the room.	Forgetting the occasion or event despite continual prompting leading up to it.
Forgetting to leave the bins out for collection.	Forgetting the process of completing regular tasks.
Forgetting where you parked the car at the shopping centre.	Getting lost in familiar locations.

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Dementia Journey

Stage	Likely happenings
Local GP Health Centre	GP will undertake a basic dementia test and look for causes. They may arrange for a blood test to be undertaken. GP may make a referral to the local Mental Health team
Mental Health Team	Average waiting time for an appointment in Northern Ireland is 6-8 months. Diagnostic testing undertaken to assist with diagnosis. Likely to be a consultant psychiatrist examining and delivering the results.
Formal Diagnosis	If diagnostic tests reveal the individual is likely to have dementia, personalised medicine may be offered (e.g. prescription medicine). A referral for a Care Manager/Social Worker to be appointed may be made.
Continue Living at Home	The individual, their family & friends are involved in this decision. A 'capacity assessment' may take place by a Care Manager/Social Worker. Domiciliary Care may be offered if eligible and available in local area.
No longer safe Living at Home	Care Manager/Social Worker make the decision alongside input from the individual, family & friends. If the individual is unwilling to accept a move into professional care a DoLS* may be required.
Professional Care Setting	The individual moves into professional care home setting for 24/7 care (Residential or Nursing).

**Deprivation of Liberties Safeguarding (DoLS) – effectively taking someone's freedom away from them for the good of their wellbeing.*

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Managing at Home - Communication

Gaining their attention

- Make eye contact with the person.
- Ensure you are in front of them where they can see you clearly – it is important that the person can clearly see your facial expressions.
- Begin by using their name and use it frequently in conversation to remind them that you are speaking to them. If you always referred to the person as ‘mum’ or ‘dad’, you may need to rethink this.

Approach from the Front

- When approaching a person with dementia always approach from the front. Research has shown that the field of vision can narrow in some forms of dementia, so you do not want to startle them.

Minimise Distractions

- Small distractions may be unnoticeable to you, but to the person with dementia they may make it very difficult for them to focus. Minimise distractions, for example, turn the TV off, close the door to prevent external noise or ensure children aren’t shouting or making lots of noise.
- When you are talking to the person, ensure that you are focusing on them and not trying to do other tasks, such as fold laundry or making tea as this may take their attention away from the content of what you are saying.

Make your reference clear

- If you are speaking to a person about something, be as specific as possible. For example, if you are telling a story about someone else, use their name and try to avoid ‘he’ or ‘she’ pronouns.
- If you are helping the person with a task, be specific about what you are asking them to do, ‘can you please pull your navy trousers on to your legs?’ rather than ‘please put them on’.

Use Short Sentences

- People with dementia may struggle with processing, so it is important to give information, instructions and ask questions in a simplistic way.
- For example, if you say ‘we need to get washed and dressed because it’s almost time for breakfast, and remember, after breakfast your daughter is visiting to take you out to lunch with your grand-daughter who is home from University’, it is likely that the person has not followed because you gave them too much information to process. Start small and build on it.

Wait for a Response

- Research has shown that a person with dementia may take up to 30 seconds to process information and respond. So, if you are asking the person if they want a cup of tea and they don’t respond instantly, give them time to process the information.
- Counting in your head may be helpful, and if they don’t respond after 30 seconds, or appear confused about the question, try and rephrase, ‘I am putting the kettle, would you a cup of tea?’.

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Managing at Home - Communication

Use Visual Cues

- this might be a hand gesture, pointing to an object or showing a picture of what you are talking about. For example, if you are offering a cup of tea, you might use your hands and facial expression to mime drinking a cup of tea.
- if you are offering choices of clothes to wear, rather than ask an open question like 'what do you want to wear?' you may hold up two tops to see which one elicits a positive response. Again, the key here is to keep it simple.

Facial Expression & Body Language

- When talking to someone it can be helpful to be on their level, or slightly below their level. If someone is sitting in a chair, do not stand over them, instead sit or kneel in front or just slightly to the side.
- Look kind and interested in the person, not frustrated.
- Try to maintain a posture that is open and your arms are not folded.
- A smile can be infectious and may be helpful in many situations, but if the individual is angry or upset, a smile may seem mocking and unhelpful.
- Be aware of your tone when speaking, aim for a calm and kind approach.

One very important rule in communication is to respond to the person's needs as you will often know them well and know what works.

Trust your instincts and learn from errors.

If something did not work yesterday or today, it is unlikely to work tomorrow- rethink, adapt your approach and try something different.

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Managing at Home – Memory Aids

There are a large range of memory aids available on the market designed specifically for dementia care. Some of these rely heavily on technology, so it is important to remember the individual's pre-dementia abilities.

Photo Albums

- Books and albums with photographs can be helpful.
- Labels with names of people in the photos and the date when they were taken can also be useful memory prompts.

Date and Time

- Try a digital clock with a large screen for the date, time, season, year etc.
- One of these displayed in a prominent location could be great aid.

Post It Notes

- Post it notes are a very helpful solution to leaving prompts around the home. These types of sticky notes tend to come in bright vibrant colours, meaning that they will catch the individual's eye.
- For example, in a bathroom a 'post it' can be put across the mirror saying 'brush your teeth'. In the kitchen, a 'post it' could be placed near the kettle to say '*have some toast with your cup of tea*', or on the oven to say '*turn the gas off*'.

Post It Notes (*cont.*)

- These sorts of prompts tend to work better in the earlier days of dementia where someone requires prompting. In the later stages of dementia, it is more likely that these notes may be overlooked, not understood or forgotten as soon as they are read.

Calendar or Journal

- In the earlier stages of dementia, a calendar or journal may be very effective. This can be used to record important upcoming events, but also to record what has occurred. This could be used to record when visitors have been at the house giving the individual with dementia a reminder of such things.
- However, as dementia progresses, it is more likely that the individual will not remember to look at the calendar or journal and may forget to record information here.

Other Memory Aids may include:

- Colour coding of keys
- Medication boxes with labels
- Smart devices (e.g. Amazon echo)
- Locator devices (for purse/wallet)

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Managing at Home – Daily Routine

When dementia begins to attack the brain the need for structure and routine does not diminish but may be more difficult to maintain.

Healthcare professionals will talk about Activities of Daily Living, commonly shortened to ADL. It includes the things we do every day such as washing, dressing, grooming, eating, exercising and engaging socially.

When an person develops dementia, it is important to try to maintain these routines. These can often be seen as somewhat of a comfort zone.

When you are providing direct care to a person with dementia, one temptation may be to do tasks for them. This is not always helpful, and this can take away vital independence which can reduce their skill set much quicker than the illness would have done naturally. Additionally, taking this independence away can lead to frustration for the person with dementia.

There are a few ways to try and help maintaining a routine.

Break the task into individual steps
Provide clear and simple instructions
Show empathy and encouragement
Offer praise

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Managing at Home – Stress Management

Whilst carers experience significant stress in the dementia journey, it is important to understand the stress levels for the individual with dementia.

The world that they once knew and understood now appears to be a very frightening place which often will make no sense to them.

The people who they trusted and turned to may now appear as the enemy.

Recognise Triggers

- If you know that taking the person out for a meal to a restaurant is a stressful event for them, you may have to accept that this is not in their best interests. Perhaps a picnic or takeaway in their own garden or house may be your best option.
- If changing a routine creates additional stress for the person, you may have to introduce changes gradually or perhaps not at all. This may mean that the person has their meals at the same time every day, or watches TV programmes at a set time

Triggers may not always be obvious, and it may take time to fully recognise. What was not a trigger two weeks ago may be a trigger now, and going forward this may change again.

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Managing at Home – Stress Management

Identify Soothers

We all have things in life that we find soothing and calming. This will be unique for every individual, and they may change across the course of the dementia journey. Some examples may be:

Hand Massage	Specific Music
Time spent outdoors	Gardening
Reading a book	Cup of tea and a chat

Physical Activity

Physical activity is good for everyone, regardless of age or health. For a person with dementia, they may have excess energy, which can lead to agitation, particularly if they are confined to a small space. It is important that we find ways for them to exercise. Depending on the persons’ own abilities, some may be able to walk for miles, whilst others may only be able to engage in armchair style exercises. Physical exercise creates serotonin and promotes endorphins in the brain, which research shows can help to improve mood and wellbeing.

Consider other similar activities that the person can do if that is what they have found enjoyable and relaxing throughout their life.

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Managing at Home – Environment

Background Noise

- In a bathroom which is fully tiled, there may be a lot of echo and the sound of the toilet flushing can appear very loud. The use of soft furnishings can help to reduce the echo and soften the tone that is heard.
- Tune in to additional background noises and analyse how they are impacting on the person. These could be the TV, radio, dog barking or road noise.

Lighting

- Good lighting is essential as it enables a person to see where they are going, see facial expressions and body language.
- Try to promote natural light where possible.
- Many low energy light bulbs provide soft light, which can be great for bedrooms, however, may not be suitable in hallways, kitchens or bathrooms.
- Try to avoid lighting which may create glare.

Kitchen & Dining

- Research reveals that dementia sufferer's appetite and sense of taste may diminish over time, so if the kitchen area provides smells of cooking it may spark the appetite of an individual.
- The kitchen needs to be organised in a logical manner so the individual can easily find what they are looking for (glass fronted cabinets can be helpful).
- Labelling food may be helpful ensuring that cooking or reheating instructions are clear on the item.
- As dementia progresses concerns may arise around the safety of the person using a cooker or other appliances. This does not necessarily mean that someone is not safe to live alone, however there may come a time when the fuse may need to be removed from the cooker and support with meals for the person.

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Managing at Home – Environment

Bedrooms

- Labelling the door with the person's 'name' and the word 'bedroom' may help to reassure them that this is where they go to bed.
- The lighting in a bedroom denotes that this is where we rest and settle for the night. Motion sensor lights which come on may be helpful, however the person may not settle unless they can actively switch off a light.
- Having colour contrasts is important so that the person can see and identify the bed clearly to include where the edges of the bed are. For example, if the carpet is a light colour the bedding could be a much darker colour to provide a contrast.
- Personalising a bedroom may also be helpful. For example, if they always had a specific dresser on which they kept certain items make sure that this remains in the bedroom (it will serve as a reference point to denote that this is their personal space).
- Sometimes people with dementia can find mirrors frightening. They may not recognise themselves and feel that they are seeing a stranger in their bedroom.

Bathrooms

- Contrasting colours often help to ensure a person can pick out items from the background. For example, coloured toilet seats, towels, clothes, toothbrush holders and soap dispensers.
- It may be useful to have grab rails, handrails and anti-slip mats fitted.
- If there is a bath, you may need to install an overflow bath plug.
- Fitting thermostats to ensure water temperature from the sink, bath and shower is controlled and cannot scald.
- If there is a shower, ideally it has level access with the floor to prevent any potential for trips. If the shower has glass doors perhaps a frosting may help to prevent potential reflections. Where there is a shower curtain, again a colour contrast may be helpful.
- Appropriate lighting in a bathroom is also important.

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Managing at Home – Environment

Gardens

- Ease of access is important so a person can find their way outside as and when they wish.
- The layout of the garden may depend on the individuals' hobbies, previous wishes and preferences.
- You may consider additional features such as bird tables/feeders if this is something which would grab the attention of the person.
- Ensuring that the garden is a secure space with no direct paths leading out of the garden and on to busy road areas.

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Medicines

Medication for Managing

Once professionally diagnosed GPs may prescribe medication to manage the symptoms of dementia.

Medication may be in the form of “inhibitors”, which help to limit the impairments on the brain. There is a vast range of inhibitors available, all designed to target specific areas relative to the type of dementia.

Depending on the type of dementia and the person’s circumstances, Health Professionals may also prescribe “mood stabilizing” medicines such as antidepressants or antipsychotics.

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Therapy

Cognitive Stimulation Therapy

Also known as CST, cognitive stimulation therapy is clinically proven to help those with mild to moderate dementia. It is the premiere therapy method for people with dementia. CST involves training memory, language ability, and problem-solving skills. Improving cognitive functioning can increase memory and reasoning skills without medication.

There is a wide range of Apps available to download on smart phones and tablets which cater for mind training skills.

Behavioural Therapy

Behavioural therapy is usually administered by qualified family or by the caregivers. Healthcare Professionals believe this method is twice as effective as antipsychotics for treating symptoms like anxiety, aggression, depression, wandering, and insomnia.

This therapy tackles the triggers or causes of unwanted behaviours like aggression or wandering. Caregivers can often pre-empt these behaviours and head them off by implementing person specific exercises.

Reality Orientation Therapy

The tools for reality orientation aim to reinforce the naming of objects and people as well as a timeline of events, past or present. This typically involves:

- Talking about orientation, including the day, time of day, date and season
- Using people's name frequently
- Discussing current events
- Referring to clocks and calendars
- Placing signs and labels on doors, cupboards, and other objects
- Asking questions about photos or other memorabilia

Validation Therapy

Validation therapy is an approach to communicating with someone who has dementia that focuses on empathy and listening.

This form of therapy is all about acknowledging the individual even if what they're saying isn't factual. This can help the person with dementia feel respected and heard.

Reminiscence Therapy

It is often used to treat severe memory loss or dementia. It works by encouraging people to revisit moments from their past. It is a form of talk therapy.

The approach may use props or sensory stimulation to spark memories. Smells and sounds from a person's past can be very effective and it can work in both one-on-one or in a group setting.



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Professional Care

A point in time may arise when the person with dementia will require 24/7 professional care. This will most likely be delivered by a care home with trained Health Professionals on hand.

Selecting a care home

Choosing a care home is important, as not all offer dementia beds. The key term to look out for is 'Category of Care'. Some care homes may only offer Residential Dementia and not Nursing Dementia, which is worth taking into considering.

Research is vital, as you may find that many care homes operate a waiting list. Arranging viewings is well worth doing, as it will help you get a feel for the care home.

Another key component of your research should be to check the regulators most recent inspection report. Normally unannounced, the inspection will provide an independent report on the care and services of the home. The regulatory bodies for the UK are:-

RQIA in Northern Ireland | **CQC** in England | **Care Inspectorate** in Scotland
Care Inspectorate in Wales

How much does it cost?

Fees are normally charged weekly and collected monthly. The weekly fee is often a combination of **Bed Rate** and **3rd Party Top Up**.

Bed Rate – this is determined by the Department of Health for the local area and is typically reviewed annually each April.

There is a set amount for Residential Care and a set amount for Nursing Care.

3rd Party Top Up – set by the care home operator, this is often linked to the quality of the accommodation, activities offered and the care offering. For example, this could be a higher ratio of staff or an extensive activities programme.

Local Health Trust operated care homes typically do not charge a 3rd Party Top Up, however almost all independent care homes will have a 3rd Party Top Up.

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Professional Care

How does the funding work?

Payment is Means Tested on an individual basis, with the assessment undertaken by the local health trust. Their assessment normally considers the individual's Income and Capital.

Income will typically include

- (1) interest on savings;
- (2) pension income (private & state); and
- (3) any social services benefits.

Capital will typically include

- (1) savings;
- (2) investments; and
- (3) property (which includes primary dwelling house).

For more information check out the authority's website – [Northern Ireland](#), [Scotland](#), [England](#) and [Wales](#).

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RESOURCES

Web Links

[Dementia - NHS](#)

[Dementia UK](#)

[NI Direct - Dementia](#)

[Age UK](#)

[Young Dementia Network](#)

[World Health Organisation](#)

[Dementia Network](#)

[Carers - UK](#)

[Carer's Allowance NI](#)

[Carer's Allowance Wales](#)

Web Links

[Dementia NI](#)

[Dementia.org](#)

[Alzheimer's Society NI](#)

[Alzheimer's Research UK](#)

[Parkinson's Foundation](#)

[Dementia Friends](#)

[Dementia Carers](#)

[Carers Trust](#)

[Carer's Allowance Scotland](#)

[Carer's Allowance England](#)

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