DEMENTIA

UNDERSTANDING YOUR DIAGNOSIS
AND
WHAT HAPPENS NEXT

Version 1 2025

Table of Contents

UNDERSTANDING YOUR DIAGNOSIS

What is dementia?

The word dementia comes from two Latin words: Demen – Mind; Tia – State of mind.

In today medical world the word dementia is an umbrella term for a group of degenerative neurological diseases.

> *"Dementia is a group of symptoms that is caused by different diseases that damage the brain. Dementia is progressive, which means symptoms may be relatively mild at first, but they get worse over time. There are many types of dementia, but Alzheimer's disease is the most common. The next most common is vascular dementia.*
> *Dementia is not a natural part of aging. It is caused when a disease damages nerve cells in the brain. Nerve cells carry messages between different parts of the brain, and to other parts of the body. As more nerve cells are damaged, the brain becomes less able to work properly. Dementia can be caused by many different diseases. These diseases affect the brain in different ways, resulting in different types of dementia." – Alzheimer's Society*

Types of dementia?

There are an estimated 100 types of dementia.
The most common being:

Alzheimer’s:

Alzheimer's disease causes the brain to shrink and brain cells to eventually die.

A gradual decline in memory, thinking, behaviour and social skills. These changes affect a person's ability to function.

Vascular dementia:

Symptoms of vascular dementia include confusion, slow thinking and changes in your mood or behaviour.

Vascular dementia is caused by reduced blood flow to the brain. It can be a result of a stroke, or the narrowing of the blood vessels in the brain.

Mixed Dementia:

'Mixed dementia' is a condition in which a person has more than one type of dementia. A combination of Alzheimer's disease and vascular dementia is the most common type.

Dementia with Lewy body:

Lewy body dementia occurs when protein deposits called Lewy bodies develop in nerve cells in the brain.

The protein deposits affect brain regions involved in thinking, memory and movement

Frontal Temporal dementia (formally known as Picks disease):

Frontotemporal dementia (FTD) is a group of disorders that occur when nerve cells in the frontal and temporal lobes of the brain are lost. This causes the lobes to shrink.

FTD can affect behaviour, personality, language, and movement.

Creutzfeldt-Jakob disease:

Creutzfeldt-Jakob (KROITS-felt YAH-kobe) disease, also known as CJD, is a rare brain disorder that leads to dementia.

It belongs to a group of human and animal diseases known as prion disorders.

Symptoms of Creutzfeldt-Jakob disease can be similar to those of Alzheimer's disease

Wernicke-Korsakoff’s dementia:

Korsakoff syndrome (also known as Korsakoff's amnesic syndrome) is a memory disorder that results from vitamin B1 deficiency and is associated with alcoholism.

Korsakoff's syndrome damages nerve cells and supporting cells in the brain and spinal cord, as well as the part of the brain involved with memory.

Parkinson’s disease and Huntington’s disease with dementia:

Parkinson's / Huntington’s disease dementia is a decline in thinking and reasoning skills that develops in some people living with Parkinson's / Huntington’s at least a year after diagnosis

The most common form is Alzheimer’s with 60/70% of diagnosed persons having this type of dementia.

Sub-types of dementia?

There are also over 200 sub-types

The type and subtype of your dementia can identify both the speed and the aggressiveness of the disease. There is no exact science to this and can vary from person to person, but it will give you a rough guide to symptoms and expectations.

Consider the more common Alzheimer's disease.

In its simplest form, Alzheimer's disease can be divided into typically 2 subtypes. There is Amnesiac Alzheimer's disease where the damage first appears in the hippocampus (memory) - this is the most typical of the Alzheimer's disease.

Then there is the Atypical Alzheimer's disease which can be subtyped into three areas:

Posterior Cortical Atrophy [PCA],

PCA affects the Occipital Lobes and the Parietal Lobes. This means that is in the early stages, memory may not be affected; things such as spatial awareness, visual impairment, hearing, and balance will be affected more

Lopogenic Progressive Aphasia [LPA], and

LPA causes damage to the left side of the Temporal Lobe and the Parietal Lobe. This means early signs would be those affecting speech, such as not being able to find the right words to say in a conversation or not following conversations.

Dysexecutive Alzheimer's Disease [DAD]

DAD affects the Frontal Lobes of the brain. Early symptoms would include difficulties with planning, organising, initiation, judgement, and the ability to make decisions.

Each one of these sub-types progress differently and affects people differently.

As the dementia progresses though, they all merge into one, commonly known as Late-Stage Dementia.

Knowing the type of dementia that you have early on, and the subtype, will mean that you will know what type of journey you are going to have, how that subtype will affect you, and what planning and support might be needed.

Dementia is different for each person and so the future can look different for each person. Based on the experience of others previously diagnosed, my own experience of watching my mom go through her journey, and my own lived experience, leads me to believe what my future will be like. My subtype is a mixed Alzheimer’s, as the disease effects all 4 quadrants of the brain. What I do not know, is how long that journey will take.

Despite not knowing how long it will take for this disease to take everything I have; I can still prepare now for that day.

Young Onset Dementia [YOD]

YOD is not a type of dementia and can be any of the types or subtypes.

YOD simply refers to the age you have been diagnosed. Anyone diagnosed before the age of 65 will be diagnosed with Young Onset Dementia followed by the type and then sub-type.

YOD is not to be confused with early onset dementia. This is a stage of dementia.

Stages of Dementia:

In its simplest form, there are three stages of dementia:

Early - Onset Dementia:

In the early stages of dementia, a person's symptoms are often relatively mild and not always easy to notice. Common early-stage symptoms include problems with memory, speed of thought, language or perception. The progression, signs and stages of dementia

Middle - Stage Dementia:

During the middle stages of Alzheimer's, damage to the brain can make it difficult to express thoughts and perform routine tasks. You may notice the person with Alzheimer's jumbling words, having trouble dressing, getting frustrated or angry, or acting in unexpected ways, such as refusing to bathe.

Late – Onset Dementia:

As dementia progresses to the late stage, the changes to the brain can lead to physical problems including mobility issues, with increased risk of falls. infections, which may cause delirium (a state of intense confusion) incontinence. difficulty with eating, drinking and swallowing leading to Palliative care.

I would not get to hung up on the stages or even trying to identify which stage the person is in. To be honest, they overlap a lot and as each person is different, so it can be very hard to tell which stage you find yourself at.

Trying to identify the stage will only cause you stress and frustrations. Dementia will take its toll, that you can be sure off. Rather focus on your life and enjoying the time you have left while you still can.

ACCEPTANCE

Getting a diagnosis of any type of dementia is extremely hard and sometimes can be difficult to accept, whether you are the person being diagnosed or a person that will now take on the role as their carer. It can be like a heavy blow to the gut!

Time and patience are needed to digest the diagnosis that you have just been given. These two attributes will be your new buzz words while you are on the journey to acceptance, but during this period, if possible, try to avoid making any major decisions. Making a major decision during this period could result in a decision that you may come to regret, or that may make it harder for you or your carer to accept the diagnosis.

So, step one is to emotionally deal with your diagnosis.

What do I mean by acceptance?

Acceptance does not mean that you stop living or that there is nothing that you can do about your diagnosis. Acceptance simply means coming to terms with your diagnosis and the limitations that this may place on you. Acceptance also implies learning to adapt to your new situation, even in the smallest of ways, which will be of immense help.

To do this, you will need support - support from your loved ones who will also be struggling to come to terms with the diagnosis (and so patience will be needed from everyone by everyone), support from medical clinicians, support from various charities, even support from technology (I found Alexa and a digital calendar helpful). Make use of these to the best of your ability. Insist on the support that you need, and sadly, it is a matter of *insisting* what you need when it comes to dementia. I found it useful speaking to a psychologist to help me deal with my emotions. I realised that this is not to everyone’s liking but I do recommend it or at least speaking to someone that you can trust and that will not judge how you're feeling.

Everything will run through your head. From “What will my future look like?” and “Will my loved ones manage to care for me and what effect it will have on them?” to “Will I be able to do certain things?” and “What about my ability to care for myself and my independence?” You will think back to the things you once could do without even thinking about it but can now no longer do either with ease or at all.

All these thoughts, though natural and certainly not wrong, are frustrating to say the least, and to linger on them is not good for your emotional or mental state.

Emotions will run high, tempers can flare, words can be said that are not meant in the heat of the moment. Speaking to someone can alleviate or, at the very least, help you to deal with these emotions.

Something you might want to consider when choosing someone to open up too:

A loved one close to you as the person you choose to open-up to about your emotions may not be the best person at this time, because they are most likely dealing with very similar, emotions. Knowing how you are struggling can make it harder for them to come to terms with the diagnosis. They will generally try to help you deal with these emotions at the expense of their own when sometimes all you need is someone to listen to you and to help you work through your questions and concerns yourself.

This is your choice though.

Once you feel ready, and that you have accepted the diagnosis, you can look to make a decision that will suit both you and your family. At that time, speak openly to all those concerned about the struggles you may be having, for example, in your own home, or if you have concern for one of your loved ones and the situation they face in their own home, try to openly discuss this with them.

I use the home situation as an example simply because this is a noticeably big decision, but it could be anything that you need support with.

I will be honest here, what I have just said may make it sound like it's easy to accept the diagnosis. It really isn’t! In fact, many people never come to terms with their diagnosis, and a family member may never accept that their father or mother has dementia which can cause major splits in a family.

Whether you accept the diagnosis or not, your father, mother, brother, sister, son, daughter, friend needs you now more than ever and your support will mean the world to them (even though they may not say so).

If you are the person diagnosed and you do not want to accept your diagnosis, or find it hard to accept, this will over time only cause you and your family frustrations. They can only do so much to support you but if you do not allow them to do so, what can they do?

Try your best to accept the diagnosis, or, at the very least, accept that you need support. Your loved ones will always be discreet - they love you, and they want the best for you, for you to be comfortable. Allow them to do so. Be open with them and keep the lines of communication open. Let them know you need some support and what support, or how much support, you need. You may need no help at all, let them know, ‘you got this!’

THE VALUE OF A GOOD SUPPORT NETWORK

What do I mean by support?

Support can come in various ways. It may be physical support you require, but it could also be emotional, psychological, financial, caring, or even all the above.

Whatever support you need or think you may need in the future, it is good to get it as early as possible. Building up a good network for support will serve you well when you need it the most.

That is easier said than done!

Building up a support network is not easy to do, especially when you require that support now, or you’re dealing with a new diagnosis. Nonetheless, it is well worth the effort.

How do you go about getting a good support network?

Dementia does not just affect the person diagnosed, it affects all of those around them, this includes the emotions that you go through. When you are diagnosed with dementia, it can often feel like the end, that there is no hope, and that soon all you will be doing is sitting in your chair with a blank face. Honestly, this could not be further from the truth!

You will, however, face some challenging emotions. Feeling down or depressed, anger, frustration, sometimes self-loathing. Many questions will run through your head, what could I have done differently to avoid this? Why me? What will my future look like? How will my loved ones react, will they care for me later? These are just some of the questions that went through my head.

Do not feel bad about these questions, it is a natural process very similar to the grieving process. Give yourself time to deal with these, and if needed, again I will stress, seek support.

Bear in mind too though, that you will not be the only one going through these emotions or who has these questions. Your closest family members, your dearest loved ones, will be going through the same emotions and asking the same questions - all too often though they bottle these up.

My advice, openly speak to each other, let each other know how you feel, what questions you have, the answers that you seek. By being open with each other you all get the best support network possible, and where you cannot support each other, or still find it a struggle, seek assistance and advice.

You might also find a support group. This may not be local but rather online; it's still worth contacting them though to start building up that network (whether you need the support now or not). If you want local support, speak to the mental health team; maybe they will be able to direct you to a support group you can go to in person.

There are many places you can go to get advice and support, though sadly they are not always openly advertised. The NHS, for example, will have a mental health team in your area. To get to speak to your mental health team speak, contact your GP and insist on a referral

Look to charities as well for support such as the Alzheimer's Society (they do not support just Alzheimer’s as the name suggests, they support and advice on all types of dementia), Dementia UK, Young Onset Dementia Network, just to name a few. Some of these charities have a help line that you can call for advice and guidance. There will probably be local charities (see signposting at the back of this booklet) that can help you with guidance as well as financial advice. These charities can support you in filling out the dreaded Personal Independence Payment (PIP) or claiming benefits. For finances, work on the proviso that if you do not ask, you will not get.

If it is more specialised support you require, then have a word with your mental health team or your doctor. They can refer you to Social Services for a social worker or an occupational therapist. Again, do this as early as possible so that you can start to plan for the future rather than waiting for that crisis point.

Why a social worker? These will be able to point you in the right direction and assist you with some of the financial, housing, and benefits needs that you may have.

Why an occupational therapist? They will be able to assist you with your physical needs as the disease progresses.

In my experience, doing this as early as possible enables you to have the contacts that you will need later. It is true you may not need them fully now, but they can help you to prepare for what is to come.

You cannot prepare for every eventuality, because for each person dementia is different. We do not know how our brain will deteriorate, but being prepared can take a little of the stress and anxiety out of the situation for both you and for the loved one caring for you.

The key to good support now and later is having the lines of communications open with as many support networks as you can.

Do not forget to sort out your Will and your Health and Wellbeing LPA (Lasting Power of Attorney) as well as your financial LPA. Plan ahead! Some of these can be done for free through legal services linked to one of the charities mentioned above.

If you are the one caring, I suggest openly speaking to your loved one about what you would like to do and follow the same guidance above.

Young onset Dementia creates a whole host of unique challenges. Unfortunately, it becomes harder to get some support especially in the financial area. That is simply because you do not fall into the Governments misinformed definition of those with dementia, that is those over the age of 65. As such, many of the support benefits will not apply to you, but if you do not ask, you will not get. You can only try. As unfair as it is, there is not much you can do if they say no. Welcome to my life!

Once you know whom to speak to or whom to go to for help and support, the help and support is there. Make use of it, you will need help and support whether you are the person living with or affected by dementia.

You can get a lot of support from people going through the same or similar situations to yours whether you are the person living with dementia or a carer.

Peer support should never be underrated, it can be invaluable. Being able to speak to people going through the same troubles you are facing, people who have been through or who are going through the acceptance stage, will help you immensely. Such ones will have different tips regarding how they deal with things or the support they have in place. You may be able to help them as well with tips you have found work for you.

The support network you build up over time will help you avoid making rash, emotional decisions, but rather more calculated, focused decisions pertaining to what would be best for you, the person living with dementia, and your loved one who cares for you so dearly.

But no matter what others tell you. You need to be open and honest with yourself. Kicking the can down the road, so to speak, will only last so long before you reach crisis stage and that is what we are trying to avoid by discussing these point early or as needed.

If you have no family

Sadly, some do not have family to call on or to care for them when struggling, and to those whom I know that are in this situation, I tip my hat too. I do not think I could cope with this disease on my own and all of life’s challenges as well.

If you are in this situation, follow the advice above. Many I speak to find that finances are the hardest struggle.

A word of warning here: we have all heard of those that take advantage of vulnerable people, and money makes people do weird and out-of-character things. Choose a friend that you trust to handle or help you with your finances or that can help you make health decisions. Get legal support for this to cover your own back so to speak. LPAs are invaluable in this case.

If, however, you do not have that trusted friend then speak to your bank and explain the situation. There will be someone at the bank who is trained in speaking and dealing with people living with dementia, and you can request that person to speak to. They can assign someone who is liable under law to help you manage your finances, so you have the safety of knowing that. You can also speak to your social worker, and they can assign someone as well. I do not think I would go the social worker route, but that is my preference.

You can also speak to the individual companies you have dealings with and explain your situation to them and see what they offer.

Either way, and whatever support you need, do not do it alone or be afraid to ask for help. Be it that of finances, help around the house, cooking. There is help out there for you – get it, get the help you need, do not struggle in silence, this disease is hard enough to live with!

Though you have no immediate family or family that are willing to care for you, there are friends out there that will take up this role with a smile, there are support networks.

Staying active physically and mentally

Staying physically and mentally active is important irrespective of whether you have dementia or not. The benefits far outweigh any negatives.

Keeping physically active can be easier said than done though when living with dementia, and if you are caring for someone, then it comes down to time. But it is not impossible.

Keep in mind the type of dementia you have, as well as how far advanced you are, when choosing what types of exercise to undertake. The last thing you want is to hurt yourself trying to do something your mind or body cannot handle, that defeats the objective. Know your limitations and adapt as you can.

I wrongly thought that forcing my body and mind to do what it has always done was the correct way; after all, this is what a lot of science and dementia specialists were saying. They were wrong! I did a lot of damage to my body, including tearing muscles and receiving bone fractures, as I lost count of my repetitions or forgot to warm up correctly, and I lost my balance a few times.

I did not give up though; I found ways to adapt.

I have also found that less active sports are better now. I found playing bowls, ten pin bowling, table tennis better for me. It uses a lot of muscle groups as well as brain power. Darts is also good for hand-to-eye coordination and brain power though not physically challenging. Swimming is good if you can. Walking for just 10 minutes a day helps greatly.

Things such as gardening, housework, moving your legs and arms while sitting, all count towards keeping active.

Reducing the frustration levels and using less brain power trying to find things helps me do the tasks I enjoy. Plus, a little help from my loved ones when I need it, even if it is them checking on me or making sure I drink.

The key is to be reasonable, use common sense, and if you struggle or feel unwell, stop, and rest. But do what you enjoy, and do not be afraid to start new things. You might be surprised what you enjoy or can do. Dementia does not spell an end to learning or trying new things.

Mental activity is just as good as physical activity.

Using your brain can only be a good thing, despite the challenges it poses. Does it slow the progression of the dementia? Science is still out on that one. My thought is that it cannot hurt to try. I am not the sort to just lay down and let things happen. I will try, then adapt, and then try again, until I can no longer do so.

Try things like jigsaw puzzles. Colouring, drawing, etc.

As the dementia progressed, the puzzle size might get smaller, then the pieces might got bigger. But keep trying, if you can.

Perhaps some jigsaw puzzle apps or games on a phone or tablet could be useful as well.

Eventually the dementia advances that much that even the adaptations no longer worked. What do you do then?

Some may tell you to force them to carry on with the activities. That caused so many arguments and tears.

We have a better understanding of dementia now to know that this ‘old style’ of caring is wrong and unbeneficial to you or the person living with dementia.

Remember what is happening to the brain - it is shrinking! The capacity to do things is dying. We would never ask a person who has lost a limb to get up and walk unaided would we? The capacity to do so is no longer available so that would be very cruel.

The same is true with the brain. If the brain’s capacity is no longer there, you cannot force the person to do something they just cannot do anymore. It is cruel and frustrating for everyone.

But, like the person who has lost a limb, it does not mean the person can no longer do other things or get around. There are aids out there to help them. Even with dementia, the brain is a very smart and powerful organ. We can find other things to do that the brain will accept.

I colour or draw using apps and find it relaxing.

Others have found they can paint, draw, make jewellery or cards, or do word or number puzzles. Whatever it is that you choose, you keep your brain active which can only be of benefit.

Remember, adapt as needed and when it is no longer fun and becomes frustrating, try something else. Keep trying.

The time will come for all of us with dementia when we do become that person people think about when we mention dementia. That is very late-stage, and we are not there yet. Until then keep physically and mentally active as much as you can, within reason.

If you need support, speak to your loved ones or the occupational therapist, they will be able to guide and assist you to keep active.

Delirium vs Dementia

What is delirium?

Delirium can be serious if left unchecked, but is very much a treatable medical condition, often caused by illness, infection, medication, dehydration, and mental or physical stress.

Symptoms of delirium

Confusion
Agitation
Low attention span or lack of interest
Difficulty thinking or remembering
Drowsiness or lethargy
Disorientation

Delirium vs Dementia

As you can read the symptoms of delirium can mimic or make the persons dementia symptoms worse, leaving it hard to identify which it is. Is it delirium or the dementia getting worse?

It is important to know because delirium is treatable and can leave no last effects if it is caught and treated early.

Dementia decline is gradual and will happen over a period of time. Changes will happen slowly hardly noticeable at first and over time get worse.

Delirium symptoms are sudden or worsen quickly, and I mean within a few hours or minutes, and you should seek medical attention as soon as possible.

Rule of thumb is simple:

THINK DELIRIUM FIRST!!

If left too long the symptoms will get worse and may become irreversible.

So, if at any time you are unsure, seek medical advice. The checks are a urine sample and bloods. It is always better to check and be sure because delirium is treatable.

Signposting and useful information

Useful Websites - UK

Alzheimer’s Society
www.Alzheimers.org.uk

Young Dementia Network
www.youngdementianetwork.org

Dementia UK
www.dementiauk.org

Lewy Body Society
www.lewybody.org

Rare Dementia Support
www.raredementiasupport.org

NHS Dementia Guide
www.nhs.uk/conditions/dementia

Useful contact information - Local

The Bridge (Dementia Advisory Service)

Free advice as well as emotional and practical support for those experiencing memory problems, diagnosed with dementia and their families.

01429 868587
thebridge@thegreathamoundation.org.uk

Hartlepool Carers

Offer support and information on issues connected with your caring role.

www.hartlepoolcarers.org.uk
01429 283095
staff@hartlepoolcarers.org.uk

Hartlepool Mental Health Services

01429 803660
www.tewv.nhs.uk/services/community-mental-health-older-hartlepool

Advice at Hart (Financial advice)

Provide advice and support on all things finances and benefits as well as form filling and tribunal representation.

www.advice-at-hart.co.uk
01429 748010
info@advice-at-hart.co.uk

Citizens' Advice Bureau

Provide advice and information on a variety of topics such as housing, debt and work.

01429 408401
enquiries@hartlepool.cabnet.org.uk

Benefits

01429 284188 (Housing and Council Tax)

Hartlepool Community Hubs

Provide a range of events, activities, health and advice services.

www.hartlepoolnow.co.uk/pages/community-hubs

Hartlepool Day Centre

Provides friendship, support, stimulation with a wide range of activities, as well as respite for carers.

01429 279005
hartlepool.daycentre@thegreathamfoundation.org.uk

Community Pastimes

Supports small groups of people who experience memory problems or diagnosed with dementia with similar interest’s and hobbies to access the wider community.

01429 871442
Community.pastimeshartlepool@thegreathamfoundation.org.uk

Social Services (Integrated Single Point of Access)

The gateway to information, support and care.

01429 523390

Hartlepool Council

01429 266522
customer.service@hartlepool.gov.uk

Council Tax
www.hartlepoolself.achieveservice.com/service/Council_Tax_Support

Active Hartlepool (Sports and physical activity)
www.activehartlepool.co.uk
active.hartlepool@hartlepool.gov.uk

Healthwatch Hartlepool
Local health and social care champion.
0800 254 5552
yoursay@healthwatchhartlepool.co.uk

Things to do as soon as possible

Lasting Power of Attorney (both financial and Health & Welfare)

Last Will and Testament

Possible Council Tax reductions

Possible reduction in water rates

Personal Independence payment (PIP)

Benefits

Notify DVLA of diagnosis

Notify insurances of diagnosis

Contact The Bridge Dementia Advisory Service

About the Author

Michael Booth - living with young onset dementia

Michael’s first experience of young onset dementia was caring for his mother, who was diagnosed at the age of 50. It took 4.5 years for Michael’s mother to receive a correct diagnosis but unfortunately, by the time she received a diagnosis she was completely nonverbal. Michael’s mom passed away from dementia 9 years after her diagnosis.

When Michael started showing similar signs to those displayed by his mother, it was suggested that he should get tested for young onset dementia.

Michael was diagnosed with young onset dementia at the age of 46. 10 years after his mom’s diagnosis. Michael found that, all though 10 years had passed, post diagnosis had not changed in that time.

But he didn’t let the lack of change, or his diagnosis define him. Since his diagnosis, Michael has been a strong advocate for change within dementia, from writing and publishing his own book to working alongside the Young Dementia Network and other major dementia-based charities, as well as with local charities.

Michael continues to help those living with dementia as well as their families and carers, which lead him to write this booklet for you, so that you can understand your diagnosis and what it is you are to be faced with – “giving you hope and courage to face the fight, so that you and your loved ones can continue to live a happy life despite dementia!”

Thanks to Michael’s involvement, he has been able to raise awareness of dementia and speak up for those living with a diagnosis. Michael continues to thrive and inspire, refusing to allow dementia to define who he is.

If you want to know more about Michael’s story, his book, ‘Dementia, you are not alone!’ is available on Amazon and other online bookstores.

In partnership with:

DEMENTIA FRIENDLY HARTLEPOOL

The Greatham Foundation

Community Led Inclusion Partnership

healthwatch Hartlepool