



**At the forefront of
young onset dementia
care in the region.**



The Manor.

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at Eighton Lodge**
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Gateshead, NE9 7UB

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Enquiries Team now on:**
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Resource
booklet.



We're here for
you every step
of the way.

The Manor.

With thanks to Dementia UK and the Young Dementia Network for allowing us to use their information and advice across this resource booklet.



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The first step in solving any problem is recognising there is one.

70k+ 2-5

Diagnosis awareness

Over 70,000 people in the UK have been diagnosed with young onset dementia. It's estimated that many more than that are still undiagnosed.

Missed diagnosis

On average a person may see between **two to five consultants** before a young onset dementia diagnosis is made.

4.4

Diagnosis delays

The average time in the UK for a young onset dementia diagnosis is **4.4 years** in younger people. Misdiagnosis, missed symptoms and a general lack of awareness all contribute to chronic delays.

41%

Diagnosis rate

The current estimated dementia diagnosis rate for under 65s is **41%**, compared to **68%** for people aged over 65.

We're here to make the difference. To offer care, support, help and advice.

Here at The Manor, we want to make it easier for those living with young onset dementia (YOD), including their family and loved ones, to find the right information and resources they need.

No matter which part of the journey you're on, whether it's identifying early signs or post diagnosis, this booklet is here to help you understand YOD. We want to offer as much support and understanding as possible to show you that you're not alone - we're with you every step of the way.

There are over 70,000 people in the UK that have been diagnosed with YOD. It has been estimated that many people are still awaiting a correct diagnosis.

We know better than anyone that YOD can be devastating, not only for those living with it, but for their friends and relatives too. Symptoms are easily missed, and support can be hard to find, which is why we've created this resource pack, designed to make sure that you have the maximum support available, all in one place.

With thanks to Dementia UK and the Young Dementia Network for allowing us to use their information and advice across this resource booklet.

Let's start by highlighting some myths about dementia.

It only affects older people

No, although the likelihood of developing dementia increases with age, people as young as 30 can show symptoms of dementia. This is called young onset dementia (YOD)

It's a natural part of ageing

No, dementia is not a natural part of ageing. It is a group of related symptoms associated with ongoing, declining brain function, and affects 1 in 11 people over the age of 65 in the UK.

People with dementia don't understand what's going on

There are many types and stages of dementia, and individuals will be affected differently. Memory loss is not always the first symptom of dementia, and many people living

with a diagnosis are still able to function independently. They may be able to continue working and living their lives as they normally would. Whether someone is or isn't fully aware of dementia, everyone deserves to be treated with dignity and respect. Whilst a person living in the later stages of dementia may not always be able to communicate with you directly, they can still recognise and understand the feelings behind your actions and words.

There's a cure and it can be prevented

There are many researchers and professionals working around the clock to better understand and treat dementia conditions, but there is currently no cure or certain preventative measures. However, there is good evidence that a healthy

lifestyle can help reduce the risk of developing dementia when you're older, and mental and physical exercises can help slow down dementia progression. There is plenty of support and research available to help those on their dementia journey.

Dementia is a death sentence

Time can be more precious when living with a dementia diagnosis, but there is no reason as to why an individual cannot continue living life to the fullest. Together, we are all fighting back against dementia to ensure that nobody lives in fear of their diagnosis. Instead, we want everyone to feel hopeful for the future.

People with dementia are violent/ aggressive

Individuals with dementia may often feel confused and frustrated, and this can affect their behaviour, with changes in their brain causing them to involuntarily act out of character. Dementia affects everyone differently, but if we are more aware and more patient with those diagnosed, we can support and understand their needs more effectively.

There's only one type of dementia

Alzheimer's is the most common form of dementia but there are over 200 types of dementia. Each type of dementia is different and has different effects, so fully understanding your own diagnosis is very important.

There are different types of dementia.

Common types of dementia

Alzheimer's disease

This is the most common form of dementia. Symptoms include memory problems, difficulty thinking, and language or perception issues.

Vascular dementia

This is the second most common type of dementia. Early symptoms include problems with concentration and planning, and short periods of confusion.

Lewy body dementia (LBD)

This is a progressive brain disorder that affects thinking, movement, mood, and behaviour.

Other common types of dementia

- ▶ Frontotemporal dementia
- ▶ Alcohol-related dementia
- ▶ HIV-associated dementia
- ▶ Dementia caused by Huntington's disease
- ▶ Creutzfeldt-Jakob disease

To gain a deeper understanding of your diagnosis and symptoms, ask your GP to give you as much detail as possible and request to see a specialist if needed.

Challenges faced by those with young onset dementia.

Challenges and disruption

Younger people experience different symptoms to older people and the impact on their lives is usually far more disruptive. Those living with YOD are more likely to still be working when they are diagnosed, with many having significant financial and personal commitments such as mortgages, children to care for and dependent parents too. All of this means they will most likely be facing a number of challenges. Here are just a few examples:

- ▶ Balancing work-life responsibilities.
- ▶ Feeling alone.
- ▶ Lack of YOD resources.
- ▶ Not being taken seriously.
- ▶ Not talked about enough due to lack of YOD awareness.

- ▶ Inadequate support and services for their age group.
- ▶ Financial difficulties.
- ▶ Misdiagnosis/ delayed diagnosis. GPs often do not code YOD cases correctly (as there isn't a code for them to use), leading to a lack of accurate data. The average time to diagnose in younger people is 4.4 years, compared to 2.2 years for older people, where there is a higher expectation of dementia.
- ▶ Lack of social funding.
- ▶ Lack of training to effectively manage the unique needs of YOD patients, limiting the quality of ongoing care, and increasing the likelihood of crisis.

Young onset dementia checklist.

Signs and symptoms

Signs and symptoms of dementia can vary depending on the type the person is living with and the stage it's at. YOD symptoms are less specific to memory issues, as we find with elderly dementia, and more to do with changes in personality, behaviour and mood.

Common symptoms

- ▶ Individuals may experience reduced empathy and emotional engagement.
- ▶ Neuropsychiatric presentations, such as increased agitation, depression, delusions, hallucinations, aggression and anxiety.
- ▶ A decline in personal care, due to a lack of motivation or awareness.

- ▶ Struggling with language and communication, showing difficulty with finding words, hesitant speech, and vague or over-complicated speech.
- ▶ Physical changes in gait, balance or mobility, fixed eye movement and signs of Parkinson's disease.
- ▶ Changes in movement and coordination, often showing signs of clumsiness.
- ▶ Changes in vision and spatial awareness, leading to issues with disorientation. This can affect misjudgment when driving, mis-reaching objects in clear view, difficulty perceiving depth, volume and distance.

- Are you aged 30-65?
- Do you feel a change in your mental sharpness?
- Do you sometimes find it difficult to find the right words?
- Is your speech more hesitant, vague or over-detailed? Do you find it difficult to 'get to the point' when speaking?
- Have you developed problems with speech, reading, managing money, figures or other mental skills?
- Are you struggling with spatial awareness? Have you noticed a change in how you walk, your balance, mobility or steadiness?
- Are you making repeated visits to your optician and finding nothing wrong?
- Are you asking the same question over again, or repeating phrases?
- Are you putting objects in unusual places?
- Are you having difficulty judging distances or mistaking reflections or patterns for other objects?

This checklist, created by the Young Dementia Network, is not intended to be used to diagnose yourself or someone else with dementia. This checklist is to be used as a guide and understanding of what to look out for with YOD. You may use this checklist to support or express your concerns to a doctor or healthcare professional.

Reaching the point of diagnosis can be a long road.

Problems with diagnosis

Getting a diagnosis for young onset dementia can be hard. With it taking on average 4.4 years to receive a diagnosis, symptoms can easily be missed.

Healthcare professionals often read symptoms as depression, anxiety, stress or menopause. To avoid these wait times, it's good to inform your doctor of any symptoms present and to go prepared.

If you're struggling to get a diagnosis but trust your gut feeling that something's not right, our home managers offer a home assessment, using our expertise and experience in dealing with dementia.

How to talk to your GP

Before an appointment, make sure you're prepared and have all your questions ready. Write down things that are a concern to you, and any symptoms you may be suffering from if there's more than one. Keep a record of any changes in symptoms, behaviour, vision or hearing, diet or any medication you're taking.

Take the Young Dementia Network's personal checklist with you so you can discuss this further with your GP. It can be quite daunting going to a GP, especially when there's so much uncertainty. Ask someone close to you to accompany you to your appointment: they can be there for support, to record conversations and share their thoughts on the situation.

For those with YOD, misdiagnosis is very common and it can sometimes take over four years to receive a correct diagnosis. Symptoms can often be mistaken for menopause or depression. This is why it's a good idea to record any changes in your life to do with moods, behaviour, vision, speech, etc.

If you have any family history of dementia, this is also something to flag to a GP as, although dementia is not usually inherited, some types do have a genetic link. There are tests you can take to see if you have specific genes related to this.

If you feel you have been misdiagnosed, continue to record changes and what's not working from things that have been

previously suggested. Stay persistent with GPs and appointments - you can request second opinions or further tests if needed.

During your appointment, it's a good idea to note down important information such as dates for appointments, support groups and potential medication. You also have the right to ask for any copies of letters that will be sent to other health and social care professionals. Make sure you've asked and have answers to all your questions.

If you're still unsure about something, don't be afraid to ask the healthcare professional to repeat or expand on any information given.

How to talk to someone living with young onset dementia.

Small changes, big difference

Remember to be calm and patient. Sometimes it's hard for someone with dementia to communicate verbally and get their words out - be patient and understanding. Here's a few small things you can do that could make a big difference:

- ▶ If someone is having difficulty finding the right word or finishing a sentence, ask them to explain it another way or listen out for clues so you can help them out.
- ▶ Always listen to them carefully.
- ▶ Offer encouragement both verbally and non-verbally, for example by making eye contact and nodding.
- ▶ Try not to interrupt someone talking as this can contribute to them losing their train of thought and break their pattern of communication.
- ▶ If they're visibly upset or distressed, try not to let things escalate by staying calm and allowing them the time they need. Don't be dismissive towards them as sometimes it's better to just listen and show support.
- ▶ Try not to over complicate sentences or conversations - keep it short and simple.
- ▶ Don't be patronising and talk to someone like a child - everyone deserves dignity and respect.
- ▶ Include them in conversations - it's important they don't feel isolated.
- ▶ Let them express themselves however they wish or in whichever way is easiest for them.
- ▶ Using prompts or pointing to things can be a good way of communicating with someone, such as pointing to photos and objects.



How to help someone who's showing signs of distress.

Keep calm and carry on

It's common for people with dementia to show signs of distress and it can be difficult and confusing for friends and relatives to calm down someone with dementia.

A person with dementia may show signs of distress, stemming from confusion about where they are, or who is with them. Changes to their routine can also cause frustration. Maintaining a routine can play an important part in avoiding a stressful situation. Here's some tips to help calm a situation.

As a family member or friend of the individual with young onset dementia, it is important to remember that you will most often be the best person to offer reassurance.

- ▶ Try to identify the cause of their distress.
- ▶ If possible, ask what is upsetting them. If they answer, listen attentively, even if they are confused.
- ▶ Try to remain calm. If the person with dementia says something upsetting, take five or ten seconds to collect your thoughts before you reply.
- ▶ Use a calm, steady tone of voice
- ▶ Try to maintain eye contact
- ▶ Try to keep their environment calm to avoid overstimulation.
- ▶ Look for physical signs of distress – for example, holding their crotch may mean they need the toilet.
- ▶ Give the person a hug or sit with them and hold their hand.
- ▶ Play their favourite film or music.
- ▶ Offer them a cup of tea and something to eat.
- ▶ Go into a different room together or into the garden for a change of scene.
- ▶ If they are distressed by a change in routine, calmly explain what is happening.
- ▶ When a person becomes more distressed despite your attempts to calm them, it can be helpful to acknowledge their feelings and then give them some space. If it's safe and appropriate, consider going into another room for a few minutes.

Our support and resources available to you.

We're here for you

Whatever stage of the journey you're on, it's essential to have access to all the different support groups and resources available to you.

The faster you act, the easier and clearer your journey will be. Receiving a diagnosis or waiting to hear back for results can be stressful, confusing and frustrating. Some people may feel lonely and isolate themselves as they can feel at a loss. A diagnosis does not define you and it certainly doesn't mean the end. We're here to make sure you continue to live your life to the fullest and to provide you and your loved ones with as much support as you may need.

The information provided in this booklet does not replace advice and opinions that doctors, pharmacists or nurses may give you.

Our homes offer:

Respite care

If you or your loved one is in need of a break, we offer a short-term care arrangement at our homes. If you'd like to try out one of our homes to see if it's the right place for you, this can also be a good option.

Permanent care

If you decide that our home is the best option for you, we can offer you a permanent bed within one of our homes, providing you and your family with the best care and support.

Daycare

We offer daycare services that operate seven days a week and run through from 8am to 6pm, with entirely flexible pick-up and drop-off times depending on your needs.

Workshops

We collaborate with many charities and groups providing dementia-friendly or age-appropriate activities and workshops. Our teams work hard to make sure each activity is fulfilling the needs of each individual and improving their health, mood and social skills. We often attend workshops held by locals or host them ourselves. To find out more about when these workshops are running, sign up to the newsletter on our website.

Home assessments

Our professionals will carry out a care assessment to determine which level of care you require and how we can fulfil and tailor to your specific needs. This is also a great opportunity to get to know and speak to our

professionals about any questions you may have.

A cuppa

Even if you'd like to just pop in for a chat, whether you've been diagnosed yourself or a loved one has been affected, our kettle is always on. We're always here to offer any friendly advice or answer any questions you may have to the best of our ability.

To find out what The Manor could offer you or a loved one, or to order our enquiry pack full of useful resources and information, **call our friendly New Care Enquiries Team now on: 0191 694 1052** or for more info explore: **dementia-wellburncare.co.uk**

Expertise through collaboration on the inside and out.

The power of collaboration

We're constantly collaborating with healthcare professionals, charities and organisations to make sure we're offering the best support and knowledge.

All our staff are dementia trained and attend regular meetings and training to ensure we're providing the best care. To find out more information regarding occupancy, prices, the services we provide, or any other queries, call our enquiry team on: 0191 694 1052 or for more information on what The Manor could offer you or a loved one, visit dementia-wellburncare.co.uk

We have many connections within our team and across our homes, providing plenty of resources and support you may need. We're more than happy to connect you to the right people if we can't provide all the answers you're looking for.



Working closely with charities dedicated to young onset dementia.

The power of collaboration

Here at The Manor, we've seen the power of collaboration first-hand: the success of The Manor has only been made possible because of it. We strive to create a warm and welcoming atmosphere that fosters a sense of connection, belonging and community.

We take community responsibilities seriously and are passionate about being a force for good. We've collaborated with many charities and organisations, with our main charity partner being Dementia Forward.

Dementia Forward has been on the journey with us ever since the conceptual stage, helping us to shape what The Manor is and what it should offer. Their knowledge and

experience of working with real families has been invaluable – our continued collaboration informs our decision-making and strategies, ensuring we're offering first-class, dedicated care.

Working with York-based Dementia Forward is just one of many relationships that demonstrate how mutually beneficial collaboration can be.

Another of our strong charity links is with Silverline Memories, a dementia charity local to our home in Gateshead. We work closely with Silverline Memories, providing support groups, workshops and activities for all those affected by dementia.

Dementia Forward
0330 057 8592
dementiaforward.org.uk

Silverline Memories
0191 603 0095
silverlinememories.com

Other useful resources and contacts.

Wheelchairs and mobility aids

0300 456 1914
redcross.uk

You may be eligible for a wheelchair or walker. Ask your GP to refer you or contact Red Cross to enquire about their wheelchair hire scheme.

'I have dementia' card

This is a card we provide that someone diagnosed with dementia can carry in case anything happens to them or if they end up somewhere confused or lost. The card will alert the reader that the person has dementia and who to contact.

Carer's Emergency Card

This is a card that a carer can carry in case anything happens to them, which says that there is a person being cared for who may be alone at home. Available from local carers' organisations or your local council.

Medical ID

You can buy medical identification jewellery including wristbands and pendants to help show what your needs are if anything happens to you. There are many types available. They may provide peace of mind in case something happens when you are out and about.

Advance Statement

An Advance Statement will help people who might care for you to know more about you – what you need, what you like and dislike, your food preferences, what you want to be called and how you want to be cared for. An Advance Statement isn't legally binding, but it must be considered.

Admiral Nurses

Admiral Nurses are specialist dementia nurses who are there for the whole family. There are local services in some areas. There is also a national helpline: 0800 888 6678

Social workers

Social workers can help you with needs assessments, helping you to find useful resources and services. To access a social worker, call your local council and request the 'adult social services' department. You can request a care needs assessment where a social worker will come and evaluate the individual's needs.

Young Dementia Network **youngdementianetwork.org**

The Young Dementia Network is a collaboration between people affected by young onset dementia and professionals and works to increase knowledge, understanding and awareness of the condition.

There's a lot of support and advice out there.

Useful charities/ organisations

Dementia Forward

0330 057 8592

dementiaforward.org.uk

Dementia Forward is a local charity supporting people living with dementia and their families across York and North Yorkshire.

Silverline Memories

0191 603 0095

silverlinememories.com

Silverline Memories is a charity in North East England providing activities and specialist support for people living with dementia and for their carers.

Dementia UK

0800 888 6678

helpline@dementia.org

Dementia UK is the specialist dementia nursing charity and provides support for families affected by dementia.

York Carers Centre

01904 715490

yorkcarerscentre.co.uk

York Carers Centre helps unpaid carers living with or caring for someone who lives in York. They provide advice and information for carers.

York Mind

01904 643364

office@yorkmind.org.uk

yorkmind.org.uk

York Mind is a leading local provider helping people recovering from mental health challenges.

Age UK

Advice line: 0800 678 1602

ageuk.org.uk

Age UK are a leading charity offering life-enhancing support for anyone affected by dementia, submit your postcode to find your closest services.

Alzheimer's Society

Dementia support line:

0333 150 3456

alzheimers.org.uk

Alzheimer's Society are a leading care and research charity for anyone affected by dementia, submit your postcode to find your closest services.

Patient Advice and Liaison Service (PALS)

01904 726262

pals@york.nhs.uk

yorkhospitals.nhs.uk

PALS offers confidential advice, support and information on health-related matters.

Dementia Matters

0191 217 1323

dementiamatters.net

Dementia Matters is a specialist dementia charity in the North East, providing support services for people living with dementia and their families in and around Newcastle.

There's a lot of support and advice out there.

Hartlepool Young Onset Dementia Group **07725 799532**

lynnkearney@ntlworld.com

Hartlepool Young Onset Dementia Group meets 1-3 times a week for a cuppa and a chat, supporting and guiding those affected.

The Bridge **01429 868587**

thebridge@hospitalofgod.org.uk

The Bridge is a free service based in Hartlepool that offers advice, information and support to enable people to live well with dementia.

Chrysalis Club Tynedale **07760 124 539** **chrysalisclub.org.uk**

info@chrysalisclub.org.uk

Chrysalis Club Tynedale provides dementia-friendly activities and support in Tynedale.

Making Waves North Tyneside **0191 607 2069** **admiralnursesNHCT@northumbria-healthcare.nhs.uk**

Making Waves North Tyneside offers a safe space to access support, meet others in a similar position and share experiences of daily life around dementia.

Tyneside and Northumberland Mind **0191 477 4545**

tynesidemind.org.uk

admin@tynesidemind.org.uk

Tyneside and Northumberland Mind offer free advice and support to people living in Newcastle experiencing a mental health problem.

Newcastle Carers **0191 275 5060**

info@newcastlecarers.org.uk

newcastlecarers.org.uk

Newcastle Carers support adults, children and young people who care for someone living in Newcastle upon Tyne.

Apps, podcasts and books.

Apps

MindMate

An inclusive application that aims to improve mental and physical wellbeing. It offers various forms of support to family members and caregivers.

Peggi

Peggi brings together all the benefits of social media to elderly, isolated or vulnerable people but without the complexity of using social media platforms.

NHS App

The NHS App gives you a simple and secure way to access a range of NHS services on your smartphone or tablet.

My House of Memories

Explore the past together with family, friends and carers.

StaySafe

StaySafe helps organisations locate remote workers in emergency situations and send assistance.

Life360 and Family360

Life360 caters to families with features like individual driver reports, location history, and geofencing.

Reflectly

Reflectly is the #1 journaling app that allows you to write your thoughts and feelings to improve your mood and practice mindfulness.

Podcasts

My Life With Dementia- a Dementia UK podcast

Listen to 'My Life with Dementia' and hear from real people who share their experiences of living with, caring for, or losing someone to dementia.

Dementia Together Podcast

Alzheimer's Society podcast where you can listen to the stories and voices of people affected by dementia in audio interviews from the Alzheimer's Society magazine.

The Dementia Researcher Podcast

A biweekly podcast for early career researchers, bringing together fantastic guests to discuss their research on Alzheimer's Disease and dementia.

Books

Who Will I Be When I Die? By Christine Bryden

Dear Alzheimer's

A Diary of Living with Dementia
by Keith Oliver

Slow Puncture

Living Well with Dementia
By Peter Berry

Somebody I Used to Know By Wendy Mitchell

Dementia, You Are Not Alone!

From the perspective of a former carer and now a person living with dementia
by Michael Booth

Other useful contacts to have at hand.

Useful contacts

It's good to talk to those closest to you if you're feeling alone. It's also important to inform those around you about your diagnosis and any symptoms you might be showing, so they know to be patient and understanding with you.

However, if you're not ready to talk to them just yet, here are some useful contacts to get in touch with if you need any help or advice. Don't shut yourself off and bottle things up - help is out there. Calls are confidential and you can remain anonymous if you wish.

To find out what The Manor could offer you or a loved one, or to order our enquiry pack full of useful resources and information, **call our friendly New Care Enquiries Team now on: 0191 694 1052**

You can also email us at:
enquiries@wellburncare.co.uk
For more info visit:
dementia-wellburncare.co.uk
Follow us at:
@dementia_wellburncare

Other useful contacts

Alzheimer's Society Helpline
0333 150 3456

Dementia UK Admiral Nurses Helpline
0800 888 6678

Carers UK
0800 808 7777

Age UK
0800 055 6112

Samaritans
116 123

You are not alone on your dementia journey. It may feel at first that resources and support for YOD are scarce and hard to find, but our

mission is to continue shouting about YOD and the impact it has on so many lives.

We are committed to ensuring that every individual living with YOD receives the highest possible level of care and support by continuing to collaborate with a wide range of stakeholders, charities, relevant support groups, and healthcare professionals.

We believe that by fostering strong partnerships with these key players in the YOD community, we can create a comprehensive support network that addresses the diverse needs of those affected by this condition, building a strong support system that helps everyone affected.



We're here for
you every step
of the way.

The Manor.