



NHS



# Living with Dementia in Hull





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# About Dementia

## What is dementia?

The word dementia describes a set of symptoms that may include memory loss, difficulties with thinking, problem-solving or language and sometimes changes in mood or behaviour. These changes are often small to start with, but for someone with dementia they can become severe enough to affect daily life.

Dementia isn't a natural part of ageing. It is caused when the brain is damaged by diseases such as Alzheimer's disease or a series of strokes. There are many diseases that result in dementia with the most common types being Alzheimer's disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementia. Sometimes people have more than one type of dementia and this is known as mixed dementia.

## What to expect

Every person with dementia is unique and will experience dementia in a way as unique as they are. The different types of dementia also affect people differently, especially in the early stages.

Although every person with dementia is unique, there are some common symptoms and these include:

- Memory Loss – having difficulty recalling things that have happened recently
- Difficulty thinking things through and planning – usual daily tasks such as cooking a meal can become hard to undertake,



dressing can be difficult. Understanding new ideas and problem solving becomes challenging

- Language – having difficulty following conversations or finding the right words for things
- Confusion about time or place – becoming confused about where you are, even in a place you know well. Losing track of the day, date or time
- Visual and sight difficulties – experiencing problems judging distances and misinterpreting patterns or reflections in mirrors
- Mood changes - becoming unusually sad, angry or frightened. Losing interest in things and becoming withdrawn. Threatening violence, psychotic episodes

Dementia is progressive, which means the symptoms gradually get worse over time. How quickly this happens can't be predicted as every person with dementia will experience dementia differently.



*Enjoying life  
as part of the  
Intergenerational  
Choir which included  
people living with  
dementia*

As dementia progresses behaviours that seem unusual or out of character may develop. These may include asking the same question over and over, pacing, restlessness or agitation. This can be distressing or challenging for the person with dementia and those close to them. Someone with dementia, especially in the later stages, may also experience physical symptoms such as muscle weakness or weight loss. Also common are changes in sleeping patterns and appetite.

## Diagnosis

Getting a diagnosis of dementia is not a single step but a process that takes time. The assessment process has various stages and tests and ends with the sharing of the diagnosis. For someone being assessed and those close to them this can be an uncertain, anxious and emotional time.

An assessment for possible dementia will:

- Exclude other conditions that may have similar symptoms and may be treatable. These include depression, chest and urinary tract infections, severe constipation, and vitamin and thyroid deficiencies
- Rule out other possible causes of confusion (e.g. poor sight or hearing), emotional changes and upsets (e.g. moving house or bereavement), or the side effects of certain drugs or combinations of drugs
- Give a person with dementia an explanation for their symptoms, taking away uncertainty over what is causing their difficulties and allowing them to start to adjust to living with dementia
- Enable a person with dementia to access treatment and information, advice and support
- Enable a person with dementia to plan and make arrangements for the future

Making a diagnosis of dementia is often difficult, particularly in the early stages. This is because there is no one simple test and early symptoms can be similar to those of lots of other common conditions, as mentioned above.

There is more than one way to begin the journey to receiving a diagnosis but most people will begin the process with a visit to their GP because they are worried.

The Department of Health & Social Care have developed some guidance called 'After diagnosis of dementia: what to expect from health and care services'. Visit [www.gov.uk](http://www.gov.uk) and search 'After Dementia Diagnosis'

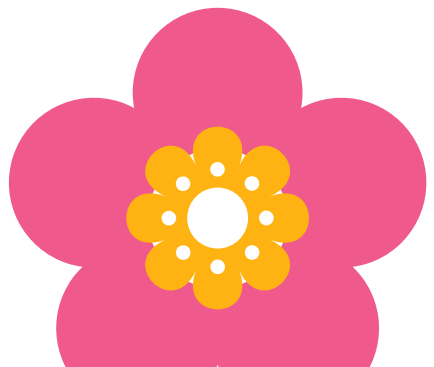
## Staying healthy

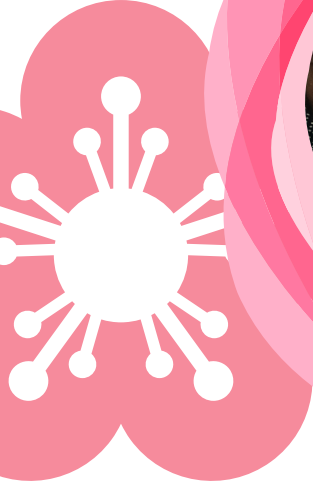
When someone has dementia, it's important that they remain as fit and healthy as possible - both physically and mentally. The better they feel, the better life will be for them and those around them. A person's health and wellbeing is affected by many different factors.

This section looks at some of these factors and the adjustments that can be made to a person's lifestyle or environment in order to boost their health.

It is important to keep in mind that a person's health will depend a lot on them as an individual. Each person will have interests, preferences and routines, as well as different physical needs and abilities. Being able to follow usual routines and continue to enjoy their interests will impact on a person's wellbeing as much as some physical factors. Alzheimer's Society have produced factsheets on a number of key points listed below:

- Mental wellbeing
- Exercise
- Eating well
- Keeping warm
- Tackling constipation
- A good night's sleep
- Smoking & alcohol
- Depression & anxiety





*Older people's activities as part of the Hull 2017 City of Culture celebrations.*

- Medication
- Check up's

All factsheets can be found at: [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

### **Safeguarding vulnerable adults**

People with dementia can be extremely vulnerable due to the nature of their condition. Symptoms can affect communication and reasoning skills and consequently they may not be able to understand or explain to others what is happening to them.

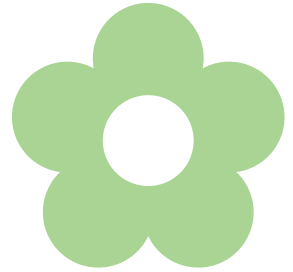
It is important to maintain their human rights and appropriate safeguards are put in place to protect them in their home and are free from abuse. A person living with dementia should be treated with dignity. Further information about types of abuse and how to recognise it can be found at [www.safeguardingadultshull.com](http://www.safeguardingadultshull.com)



## Safety in the home

A person's home can help or hinder their ability to live well with dementia. Poorly fitted mats or poor lighting can lead to trips and falls. Forgetfulness can result in a cooker being left on or a tap left running. A lack of spatial awareness (to be aware of yourself in the space around you) can lead to someone walking into a table, chairs or other furniture or objects. Disorientation can result in someone getting lost in their own home – perhaps being unable to find the bathroom, bedroom or kitchen.

The person can be encouraged to talk about potential improvements (designed to enable them to live independently in their own home).



These can include:

- removing ill-fitted mats
- re-arranging furniture to help them move more easily around individual rooms
- putting on lights to help improve visibility in the home
- pulling back net curtains to allow more natural light into rooms
- installing simple devices to avoid sinks and baths overflowing
- fitting sensors to monitor movement in the home, particularly at night
- putting cleaning fluids out of reach and removing medicines that are no longer needed (that is, taking them to the chemist)
- fitting smoke alarms and ensuring that fireguards are placed in front of open fires
- putting simple signs on doors and cupboards to make it easier to find rooms and objects (such as cups, saucers and cutlery).

More information can be found in the Dementia-friendly environments section of the SCIE website [www.scie.org.uk](http://www.scie.org.uk)



## What to expect if you attend or are admitted to hospital

If you are over 75 and are admitted urgently to hospital you should be assessed for confusion and memory problems. So for some people their assessment will begin in hospital.



Admission to hospital can be very a very difficult time for patients and their families / carers. The Butterfly Scheme allows patients with dementia or delirium to opt in to the scheme by choosing to display a discreet Butterfly symbol on their record, which lets staff know that you may need extra support.



The blue symbol is used by people with a diagnosis of dementia.



The outline symbol is used by anyone who may need memory support whilst in hospital.



## John's Campaign

Dr John Gerrard was diagnosed with Alzheimer's (a disease that affects the brain's nerve cells and leads to memory loss). In February 2014, aged 86, he went into a hospital because he had infected leg ulcers. Although he was strong when he went into hospital, his condition deteriorated greatly while he was there. His family felt certain that if he had not spent five weeks without people he knew to help and comfort him, he would not have deteriorated so much.

The hospital he was in provided great care; but they couldn't sit and talk to him, read to him, and keep him involved. John Gerrard passed away in November 2014. John's daughter Nicci Gerrard co-founded John's Campaign, with her friend Julia Jones to appeal for the right for family members or trusted friends to be by the side of people who would benefit immensely from this while they are in hospital.

Staff at Hull and East Yorkshire Hospitals NHS Trust welcome carers over and above allocated visiting times. Our staff will provide you with a carer's badge. If you are a Carer or provide support to someone in hospital, we ask that you let us know what they are able to do at home, particularly their hobbies or interests. Please share with us any aspects of care you feel need to continue in hospital and which areas you are concerned about. We would like you to help us ensure their hospital stay is comfortable, personalised and safe for them. You can do this by letting us know if there are elements of care that you would like to help to provide. We want you to feel completely involved and supported, this may be assisting with physical care, attending to personal care, just sitting with them sharing memories, making them feel safe with a familiar face close by or assisting with meal

times. Relatives and carers will be welcomed and encouraged to be involved at every point of care in the patient's journey from outpatients to the theatre entrance; at tea time and overnight; during periods of planned or emergency care; every day, every time. Just knowing that you are there can be a great help to the patient. We want you to know that your involvement is always welcome.

### **What John's campaign does:-**

- Gives a carer the right to stay with a patient who has dementia
- Welcomes a carer to stay beyond the allocated visiting times
- Can improve communication between carers and ward staff
- Offers reassurance to the patient that a familiar face will stay with them

### **What John's campaign doesn't do:-**

- Provide a hotel service for friends/relatives
- Expect the carer to carry out a full range of caring for the patient
- Doesn't give priority for treatment

### **Carers must:-**

Maintain Health and Safety rules (e.g. handwashing), maintain confidentiality and may be asked to leave an area (e.g. during consultant rounds or treatments).

For more info please visit [www.johnscampaign.org.uk](http://www.johnscampaign.org.uk)

The logo for the 'STAY WITH ME' campaign. The word 'STAY' is in blue, 'WITH' is in red, and 'ME' is in green. Each word is written in a stylized, slightly irregular font. There are small blue dots between 'STAY' and 'WITH', and between 'WITH' and 'ME'. The letters are all uppercase.

## **Delirium**

Delirium is a common, serious but often treatable condition that starts suddenly in someone who is unwell.

## **What are the effects of delirium?**

It causes a person to become easily distracted and more confused than normal. Delirium can be very distressing for the person and their family.

Delirium is different from dementia. For someone with delirium, symptoms come on over a matter of hours or a few days. The symptoms of dementia come on slowly, over a period of months or even years. Delirium is much more common in older people, especially those with dementia.

## **Symptoms of delerium**

The symptoms of delirium will start suddenly and may come and go over the course of the day. They can be worse in the evening or at night. A person with delirium will show some of the following changes:

- Being more confused than normal
- Changes in alertness – such as being either unusually sleepy or agitated
- Having a lack of concentration or becoming easily distracted
- Becoming disorientated – not knowing where they are or what day it is
- Rambling speech
- Showing changes in behaviour
- Having disturbed patterns of sleeping and waking
- Being prone to rapid swings in emotion
- Experiencing hallucinations
- Having abnormal or paranoid beliefs

In many older people, and especially those with dementia, delirium causes them to be abnormally withdrawn and sleepy. This is known as 'hypoactive' delirium and it can easily be missed or mistaken for depression, even by a health professional. Sometimes delirium makes a person abnormally alert, restless or agitated, and possibly even aggressive. This is known as



*Jean Bishop helps raise awareness during Dementia Awareness Day in Hull.*

'hyperactive' delirium. The person may have hallucinations (seeing or hearing things that aren't really there) or delusions (strongly believing things that are not true, for example that others are trying to harm them). People can also alternate between hypoactive and hyperactive delirium over the day. This is known as 'mixed' delirium.

If someone develops any of the symptoms mentioned above they should see a doctor urgently to find out the cause. Someone who knows the person should go along with them. They should tell the doctor that these symptoms are not normal for the person. This is particularly important if the person has dementia. Someone can have both delirium and dementia. It can sometimes be difficult to tell what is causing a person's symptoms. This is because some of the symptoms of delirium (for example confusion, agitation and delusions) can be similar to the symptoms of dementia, but there are important differences.

Delirium starts suddenly (over a period of hours or days) but dementia does not. The symptoms of delirium will also vary a lot over the day, but those of dementia generally don't. The exception to this is dementia with Lewy bodies, which has many of the same symptoms as delirium.

## Progression of dementia

### Advanced care planning

Advance care planning allows you to make plans for the future. If there comes a time when you no longer have capacity to make decisions, your advanced care plan will tell people what you want regarding your care and support.

The Mental Capacity Act gives a range of ways you can plan ahead. This includes Lasting Power of Attorney for your financial and also health wishes. You can also make an Advanced Decision to Refuse Treatment.

If possible, making future plans should be done as early as you feel able so that your wishes are known if you lose the capacity to make those decisions for yourself in the future. This can be done with the help of your GP.

It is important to see a solicitor as early as possible as they will also make a judgement as to whether the person is capable of making their own decision at that time.



## Support for you to live independently

### Dementia Advisor Service

Dementia Advisors support people who have had a diagnosis of dementia and their carers. The service offers practical support to understand your diagnosis and help you and your carer live independently and plan for the future.

The Dementia Advisors work in the community and work closely with GP Practices and the Memory Clinic in Hull.

The Dementia Advisors are provided by Alzheimer's Society. Alzheimer's Society provide a range of support services for people with dementia, their families and carers.

To contact the Dementia Advisor service please call 01482 211255 or visit [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

### Benefit advice

Hull Advice is a service provided by Hull City Council. It provides free impartial advice for Hull residents on a whole range of issues including benefits, debt, housing, family, community care and employment. Hull Advice will work on behalf of the customer, even if the customer has a dispute with the Council.

Hull Advice provides services through either a drop-in session or by appointment. There is also a specialist welfare rights team





who will help people with complex benefit issues. This includes representing people at benefit appeal hearings.

All of the advice given is free of charge, independent and confidential.

Hull Advice is based on 1st Floor, The Wilson Centre, Alfred Gelder Street, Hull HU1 2AG or telephone 01482 300303.

### **Adult social care**

Hull's Adult Social Care promotes a lifestyle not a service, this means they will work with you to enable you to maximise your independence and promote your wellbeing.

For information on what support is available in the community please visit our website [hull.connecttosupport.org](http://hull.connecttosupport.org)

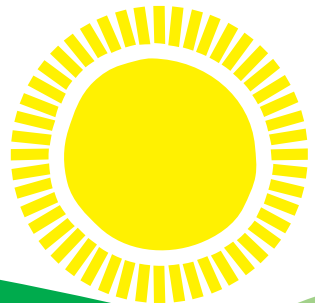
If you cannot find what you need on connect to support, please contact us for a conversation about how we may be able to assist on 01482 300300.

### **Assistive technology**

There is a wide range of technology that can support you to live independently in your own home.

There are a number of devices available from Hull City Council, that are connected to 24/7 call centre, should you need support. There are also devices such as tablets for people and carers.

- Pendant alarms
- Medication reminders
- Falls detectors
- Smoke detectors
- Flood detectors
- Cold alarms





*Hull residents  
enjoy a dance  
during Older  
People's  
Celebration Day  
2017.*

For information call 01482 300300 or visit [www.hull.gov.uk](http://www.hull.gov.uk)

MyHomeHelper has been developed in Hull and is a digital memory and communication aid for people living in their own homes who have cognitive impairment, such as dementia, learning difficulties and head injuries. MyHomeHelper includes a Calendar Clock, Diary, Reminders, News Headlines, Photos, Instant Messaging and Skype Video Calls which can all be accessed, setup and maintained by family and friends over the internet, helping to reduce anxiety, boredom and loneliness.

For more information, visit [www.myhomehelper.co.uk](http://www.myhomehelper.co.uk)




## The Herbert Protocol



Do you have a friend or relative who is elderly, suffers with dementia or has other mental health issues which can leave them confused, lost or disorientated? Nothing is more worrying or distressing than if someone you care about goes missing or doesn't return home when expected. For people living with or caring for someone with dementia or other mental health conditions, this may be quite a common occurrence. The Herbert Protocol (a national scheme) encourages carers, families, friends or neighbours; to print out and fill in this form with as much detail as possible, then keep it somewhere safe, along with a recent photo.

That way, if the worst does happen, you can give us all the information we need to start the search straight away and you don't have to think about significant dates or places when you're worried and upset:

- Print out and complete the form as soon as possible - [www.humberside.police.uk/herbert-protocol](http://www.humberside.police.uk/herbert-protocol)
- If a relative or friend goes missing, call us on 999, tell us you have completed a Herbert Protocol form and make sure you have it to hand
- Keep the completed form in a safe but prominent position where you can find it quickly. We will only ask for it if the person it refers to has been reported missing
- If you don't understand some of the terms on the form - don't worry, just complete as much as you can
- We will use the information to help find the missing person. It will be stored securely and only shared with other agencies if there is a need to safeguard someone



*Two people take to the dance floor during Older People's Celebration week.*

## Support for family and carers

### Carers Information & Support Service

The Carers Information and Support Service support unpaid carers in Hull; provide practical advice and information on your entitlements and identify community services that are available to you and the person/s you care for, putting you in touch with other carers, groups, training and events to help you not to feel isolated.

Being an unpaid carer can be fulfilling but it can also affect your health, relationships, family, job, finances and leisure time.

We offer a comprehensive assessment to help you balance commitments. You can book a confidential appointment with a Carer Support Worker who will help you work out what you need and how to get it and provide you with an individual support plan.

Please contact Tel 01482 222 220 or e-mail [chcp.carersinfo@nhs.net](mailto:chcp.carersinfo@nhs.net)

### Dementia Academy

The Hull Dementia Academy offers free dementia training to anyone living or working in Hull.

The course is aimed at families, carers and professionals and enables people to explore the nature and effects of dementia. The course focuses on effective communication skills, practical and effective ways of responding to behaviours and emotions, the concept of unmet need, why potentially “challenging” behaviour occurs and how to interact more positively with people with dementia.



For more information contact, tel: 01482 612442 or e-mail [learninganddevelopment@hullcc.gov.uk](mailto:learninganddevelopment@hullcc.gov.uk)

## **Butterflies Memory Loss Support Group**

Butterflies Memory Loss Support Group was started by June Cooke back in 2010 after her Dad, George, was diagnosed with Alzheimer's a year previously. At that time there was very little available for June's Mum and Dad to attend together to encourage them to continue their social lives. They had built up friendships with other carers and cared for participants on a research project lead by the Hull Memory Clinic. Realising the importance of peer support after a diagnosis, where people can share their experiences, fears and laugh together when the project came to an end, the Butterflies was formed.

Initially the group wanted to provide a social outlet with a variety of activities, it was also important to the founding members that they aimed to reduce stigma and increase understanding in the community. Butterflies works very closely with a number of schools, colleges and youth organisations in the hope to raise future generations with a greater understanding of how to support people with dementia at home and in the community.

A very important service they provide is training in dementia awareness to family carers to help give them the tools to support their loved one at home for as long as possible. The aim is to make life easier when living with dementia.

From its beginning of one monthly session in East Hull, the group now has a monthly session in North Hull, West Hull, Cottingham and Central Hull and a weekly luncheon club for men with support for the lady carers. After running as a voluntary group for several years, Butterflies finally took charitable status in 2015.

The group is passionate about improving life for those living with dementia and June is currently chair of a steering group aiming to make communities and businesses in Hull dementia friendly. At

the bi-monthly Voice and Influence Forum, people with dementia and their carers are able to help shape the services offered in the city by highlighting the strengths and areas of improvement in the services they receive.

The group is always welcome to new members and can be contacted on 07821 519212 or more information can be found at [www.butterflies.org.uk](http://www.butterflies.org.uk)



## Support in crisis

### Older People’s mental health services and crisis response for Hull and East Riding patients

Rapid Response Service -  
Email referrals to:  
Address:

Referrals & Enquiries: 01482 301701  
[HNF-TR.RapidResponseService@nhs.net](mailto:HNF-TR.RapidResponseService@nhs.net)  
Rapid Response Service  
Miranda House  
Gladstone Street  
Hull, HU3 2RT

The Rapid Response Service is accessible by self-referral using the contact details above or your GP can refer you. The service includes a 24/7 Triage Referral and Advice Centre based within Miranda House with sufficient senior clinicians to support you and your carer 24 hours a day, 7 days per week. All referrals and enquiries will be responded to in a timely manner with the following outcomes:

- Advice and signposting, or an
- agreement to complete an assessment

This could be through a booked appointment at one of the many assessment clinics. If your need requires a more rapid response with an assessment on the same day, this will be conducted, in the majority of cases, in your own home.

Following the assessment, further signposting and advice may be provided or it may indicate a need for further care and treatment. This will be through a referral into one of our Community Mental Health Teams for a coordinated package of care. Should acute mental health care be required, the new service will arrange either an admission to hospital or, if indicated, an Intensive Home Based Treatment intervention for you.

## **About the Dementia Collaborative**

The Dementia Collaborative is a group of organisations from across Hull who work with people living with dementia as well as their carers. Our membership includes health and social care organisations, the voluntary sector and people living with dementia and their carers.

Our goal is to improve the lives of people living with dementia; from the person affected by the disease, to their carers, friends and family members.

We meet on a regular basis and work to ensure that the best possible care is provided by all organisations to those living with dementia.

We are proud of our achievements to date, one of which is this booklet, and look forward to what we can achieve in the future.

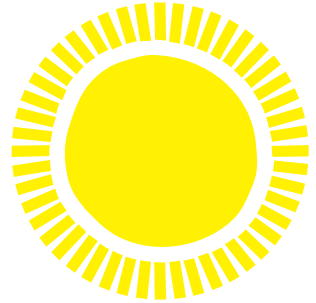
**Dr Angharad Symes - Chair**



## **Dementia collaborative**

The Dementia Collaborative is made up of the following organisations

- NHS Hull Clinical Commissioning Group
- Hull City Council
- Butterflies Memory Loss Support Group
- Hull Dementia Action Alliance
- Dove House Hospice
- Alzheimer's Society
- Hull & East Yorkshire Hospitals NHS Trust
- Humber NHS Foundation Trust
- NHS England – Yorkshire & Humber Clinical Network for Dementia
- City Health Care Partnership CIC
- Healthwatch Kingston upon Hull
- Dementia Academy



## **Voice & Influence Forum**

The Voice & Influence Forum is a group where people living with dementia and their carers meet bi-monthly to discuss topics that matter most for them. This can include improving information on advice and support.

It also discusses the collaboratives' work priorities and lets people have their say on these in order to improve services across the city.

To find out more please contact [butterfliesmlsg@yahoo.co.uk](mailto:butterfliesmlsg@yahoo.co.uk)





**Hull**  
City Council



**NHS**

**Hull**

Clinical Commissioning Group



**NHS Hull Clinical Commissioning Group**

**2nd Floor**

**Wilberforce Court**

**Alfred Gelder Street**

**Hull**

**HU1 1UY**

**01482 344700**

**[www.hullccg.nhs.uk](http://www.hullccg.nhs.uk)**

