



SUFFOLK
for mental wealth
Supporting a positive
mental health experience

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Focus on Dementia and Human Rights Part 1

What are Human Rights?

Human Rights are a set of basic rights and freedoms that we all have because we are human. These rights apply to everyone; we are born with them, and although they can sometimes be limited or restricted, such as being detained under the Mental Health Act, they cannot be taken away.

This factsheet gives a short overview of the relationship between dementia and human rights, with signposting to organisations that can provide further indepth advice, support and information. We will start with 'What is Dementia?'

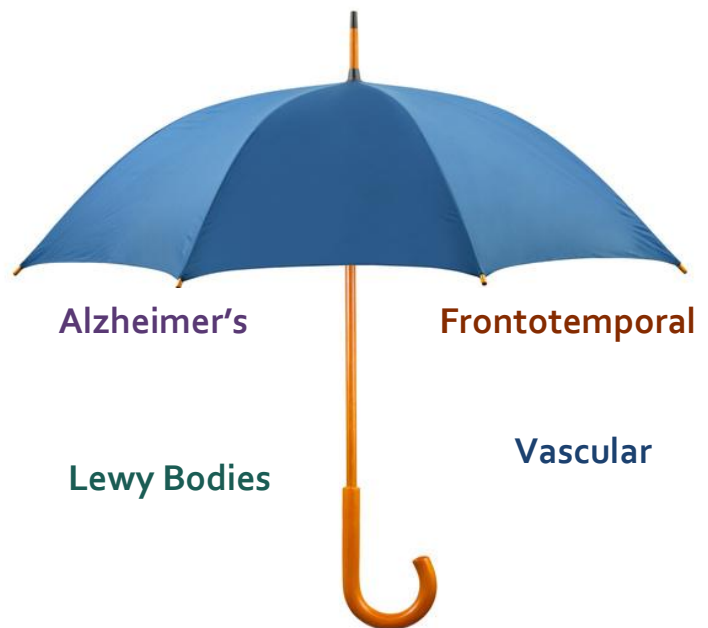
What is Dementia?

Dementia is not a disease in itself. Dementia is a word used to describe a group of symptoms that occur when brain cells stop working properly.

This happens inside specific areas of the brain, which can affect how you think, remember and communicate. It will affect mental capacity to make every day decisions.

Alzheimer's disease is the most common cause of dementia, but there are other types of dementia too. It is possible to have more than one type of dementia at the same time. Alzheimer's is sometimes seen with vascular dementia or Dementia with Lewy Bodies (DLB), abnormal deposits of protein in the brain.

Dementia is an 'umbrella term' for a decline in mental ability severe enough to interfere with daily life.



800,000 people in the UK are living with some form of dementia

- More than 42,000 of those are under 65
- 670,000 family and friends were primary care givers
- In 2014 it was estimated dementia cost the UK economy £26.3 billion.



How is dementia diagnosed?

Dementia is notoriously difficult to diagnose in its early stages, and can be masked by other physical conditions. Often the signs that somebody has early stages dementia are there, such as losing keys, forgetting pin numbers, but as we all do this it is often shrugged off.

If your GP suspects dementia, you are likely to be referred to a memory clinic or specialist. When you see your GP with concerns about your memory or thinking, they will ask you about your symptoms and medical history. They may also speak with your partner or someone close to you about your symptoms. You may be asked some questions relating to your memory and have a physical check-up. There is a range of memory tests available, and you might take one or more of these during your assessment. Because dementia usually gets worse over time, the tests may be repeated, perhaps every six to 12 months, to see if there have been any



If you are concerned about your own health, your partner, parent or friend then visit your GP in the first instance.

It is possible to live well with dementia



Is Dementia a terminal illness?

Dementia shortens life expectancy, but it is very difficult to know how long someone with dementia will live for. If the person also has another life-limiting illness, their condition is likely to worsen in a more predictable way over a period of weeks or days. This may mean that the person dies from another condition (eg cancer) when their dementia is at a relatively early stage.

But someone with later-stage dementia without another life-limiting illness often deteriorates slowly over many months. They gradually become more frail, have more frequent falls or infections, become less mobile, sleep more, and eat and talk less. For someone with later-stage dementia, the most common immediate cause of death is an infection such as pneumonia.

What should happen if someone you know is showing signs of dementia?

Obtain a diagnosis - Timely Diagnosis, integrated care plan, review within the first year.

Supporting well – access to safe high quality health and social care for people with dementia and their carers

Living Well – people with dementia can live normally in safe and accepting communities.

Dying Well- people living with dementia die with dignity in the place of their choosing.

For more information and details of sources of support, read the Alzheimers Society factsheet "After a Diagnosis".

https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=122



On Your Dementia Journey, Remember The Smiles, Love & Laughter.

Circles of Support for People with Dementia



The National Development Team for Inclusion (NDTi) led a project to work with people with Dementia to develop Circles of Support.

A Circle of Support is a group of people who help the person with dementia think about how they can maintain or enhance their enjoyment of life and what support they need to do this. The group (which can be large or small and include family, friends and professional supporters) then works together, with the person with dementia at the heart of decisions, to create new connections and opportunities.

People living with dementia who took part in the project are doing more of what they want and feeling less isolated. Other positive outcomes include the creation of mutual peer support groups, improved relationships with carers and enhanced social networks. This enhanced support can help people to achieve outcomes such as continuing to live at home and sustaining employment. Staff at partner organisations are thinking and acting differently; more broadly and creatively, focusing on networks, and having different conversations about people's lives.

For more information about this project visit :-

<http://www.ndti.org.uk/major-projects/current/circles-of-support-for-people-with-dementia>

Focus on Dementia and Human Rights

Elizabeth Moad gives a personal account of her experience of her Mum's dementia.

When the formal diagnosis of Mum's dementia was given, it confirmed what we already knew and had probably known for a long time if we really looked back. Mums altered behaviour over the years was subtle, no sudden changes and nothing to pinpoint until the forgetfulness could not be ignored with a significant instance of Mum leaving her handbag in town. Mum was prescribed 'Aricept' which is a drug treatment for Alzheimer's disease. It was only a short prescription as it delays the onset of the disease, and we didn't see any difference in Mum with Aricept. My Dad continued to look after Mum and I would call in to see them along with my sisters.

When Mum went missing one cold March day it brought home what dementia actually meant. Mum went out for a walk, as she did regularly on a route she always took, but she didn't come back. I was at their house that day and listening to my Dad file Mum as a "missing person" to the police and describe what she was wearing, was upsetting. Mum was found having walked 7 miles from home – she was safe, confused but not upset at all, just a bit hungry. After that Mum wasn't left alone and didn't go out by herself – this was for her own safety as the danger that Mum could not cross a road or find her way.

It was about this time a Power of Attorney was obtained. Mum did have capacity to understand and the Power of Attorney meant that later, when Mum no longer had mental capacity, then my Dad had the legal right to make decisions on her behalf both financial and for her welfare.

As the dementia progressed Mum could not get the sequence of dressing right, blouses on top of jumpers, shoes on the wrong foot, and needed to be helped. Mums continual repetition of questions or statements became pretty difficult for us, when Mum got in a "loop" she could ask the same question again and again and again, without remembering the answer. And Mum needed help eating – in the early stages of Mums dementia we went out to a café and I cut up Mums food for her as she was loosing the ability to use a knife and fork. People around us stared. For me being 'Dementia Friendly' is not staring but accepting. Mum was not a child, she was loosing skills as the disease progressed and became 'child like' in some ways, but she was still my Mum.

Then Mum went missing again, she didn't turn right for the conservatory but took a left out the gate and walked in to town. The police found her and I went and collected her – she was sat quite content in a police car "shall we go home Mum?" – "yes I think so." Dad put locks on the gate, and this was not a deprivation of liberty. Mum was continually looking to go "home" and that was her home of her childhood not recognising the current house as her home. Her recent memories were lost and she wanted her parents. However even at the end of Mums life she recognized my voice.

Dad had been her primary carer and I was secondary carer – it was when Dad broke his arm one Saturday that changed all this. As I wheeled Mum in to A&E to find Dad, she didn't recognize him and that was hard. On the Monday we had to place Mum in a nursing home on a temporary basis as Dad could not dress, wash, feed Mum whilst his arm mended. Leaving Mum in a nursing home and driving away, was as hard to deal with as her death two years later. Relinquishing Mums care to strangers was awful. Being a carer and then effectively becoming a visitor was a huge change.

Mum deteriorated quickly, then stabilized and didn't leave a nursing home until she died. All her life Mum was fit, active, didn't drink alcohol, didn't smoke, ate and drank everything in moderation – she was healthy and never over weight. Dementia does not have a clear link to lifestyle, it can affect anyone.



If you have a personal story to tell we would like to hear from you.

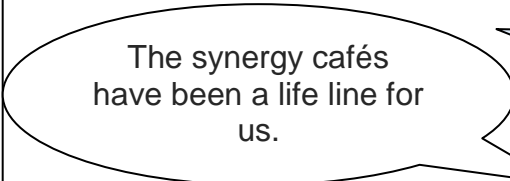
Service User Feedback

Wendy Shepherd , Service User and Engagement Lead for SUF has been to all the Synergy Cafes in Suffolk, talking and listening to people and here is what the feedback has been:-

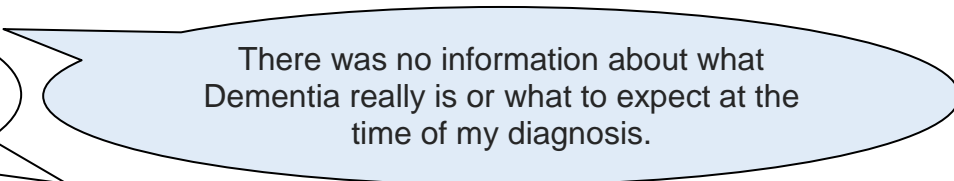
I have vascular dementia; I was given my diagnosis by a Doctor over the phone. I have not been offered any support or had any follow up appointment. I don't really know much about it really, or what it means for me.

I was given my diagnosis by my GP. I wasn't really given any information and my GP was not really aware of what support is available.

I care for my husband with dementia; our GP said that his mental health problems were part of this condition. I asked for more help but our GP said that any referral for support would not be beneficial. I was signposted to the Suffolk wellbeing service for advice, but they could not really help me.



The synergy cafés
have been a life line for
us.



There was no information about what
Dementia really is or what to expect at the
time of my diagnosis.

My wife was given medication when she was diagnosed with dementia, but we have not been given any follow up appointments to see if it's the right dose, or to discuss how things are going.

I have had no support at all.

I was diagnosed with dementia and sunk into a really deep depression. Being part of the Synergy Café in Felixstowe has helped me enormously and has given me a sense of purpose again. Its helped lift my depression.

I really value the Synergy café in Hadleigh, but I am worried. I was in another group before that closed down due to funding cuts. I am so worried about losing this group too.

I did not get any information or signposting when my GP gave me my diagnosis, no information at all. I then received really mixed and conflicting information from different organisations and was finally helped by Suffolk Family Carers. In an ideal world one would get a diagnosis and then go to a one stop shop for support and information.

I felt let down all along the line after my husband was diagnosed with dementia. I felt there were hurdles put in the way that needed getting over. Misinformation about benefits, which for me resulted in us not getting what we were entitled to for 2 years.

It's really difficult, especially as a carer. I broke my ankle and I just could not cope. I could not care for my husband for 3 weeks when I was in plaster. Because we have savings, I could not get any support and had to pay for my husband to stay at a care home for 3 weeks. There is very little support or funding for someone with savings.

The synergy café is a life line. It reduces isolation and is a great source for reliable information.

I have spoken to other people and can see that diagnosis and support just varies so much across the County. It's just not consistent at all. A post code lottery.

SUF has taken these comments to Healthwatch Suffolk and key people in dementia services. If you have a comment or experience about services in Suffolk we want to hear from you, please contact us 01473 907087.

Focus on Dementia and Human Rights

Suffolk Dementia Helpline Tel: 01473 353350



Need a listening ear, support or information on dementia? The Dementia Helpline offers information, support and a listening ear to anyone living in Suffolk.

Office hours (Monday - Friday, 9am - 5pm) and evenings

The helpline is manned by Sue Ryder trained staff and volunteers. They can offer practical support and information about dementia, along with details of other services in your local area that can help.

Help and support for people with dementia and their carers

AgeUK Suffolk - works with and for older people in Suffolk, campaigns with them and on their behalf and is a provider of direct services and support across the county.

www.ageuk.org.uk/suffolk

Alzheimer's Society

National Dementia Helpline on [0300 222 1122](tel:03002221122) can provide information, support, guidance and signposting to other appropriate organisations.

www.alzheimers.org.uk

Suffolk Family Carers - Anyone can become a family carer; their life may be restricted because they provide unpaid care to a family member, friend, or neighbor.

Information Line 01473 835477

www.suffolkfamilycarers.org



Sue Ryder Synergy Cafés proven to improve the dementia journey



Welcoming people with dementia, their family and friends
Spend time in a relaxed and supportive environment:

- Enjoy socialising with others living with dementia
- Relax, chat or take part in enjoyable activities
- Receive information and practical support

Attendance at cafés, including activities, is free. Food and refreshments can be purchased.

Cafés run weekly at the following locations:

Felixstowe, Sudbury, Haverhill, Ipswich, Shotley Peninsula (fortnightly), Lowestoft, Bury St. Edmunds, Hadleigh, Newmarket, Stowmarket

<http://www.sueryder.org/how-we-help/care-services/synergy-cafes/synergy-suffolk>

Advocacy Services in Suffolk

Advocacy means getting support from another person to help you express your views and wishes, and to help make sure your voice is heard. Someone who helps you in this way is called your advocate.



SUF Mental Health Advocacy

I know I have rights, choices and a voice

Together with VoiceAbility, SUF will from April 2016, pilot a new way of offering information about rights and choices, to support a greater focus on the quality of advocacy for mental health in Suffolk. The SUF Mental Health Advocate will hold regular inpatient/ward based 'drop in' sessions providing information and referral to the professional Independent Mental Health Advocate (IMHA) where appropriate.

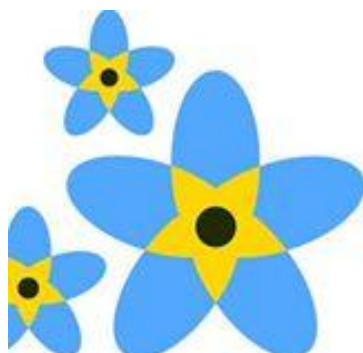
James Woolnough (pictured below right) joins SUF in May 2016 as our Mental Health Advocate. He has worked in mental health and the voluntary sector for a number of years and brings a lot of experience to the role. James will be contactable via the SUF office on tel 01473 907087.

www.suffolkuserforum.co.uk

TotalVoice
Suffolk

Total Voice Suffolk provides free, independent and confidential advocacy services in Suffolk. Advocacy and self advocacy can be vital for people who cannot speak up for themselves, or people who feel that they do not have the power to do so. Contact Total Voice tel 01473 857631

www.totalvoicesuffolk.org



Dementia Friends
An Alzheimer's Society initiative

www.dementiafriends.org.uk

SUF staff and trustees attended Dementia Friends training run by the Alzheimer's Society. SUF is now proud to be a Dementia Friendly organization and would recommend this training to others.



Changing Lives

Bringing Human Rights to Life in **SUFFOLK**



Reuniting a separated older couple

Protecting the right to family life of an older couple who relied completely on each other. An advocacy example, without court action.

Beryll and Richard Driscoll had been married for over 65 years. They had spent very little time apart and by 2006 she was blind and he could not walk unaided. He was her eyes and she helped him to walk. When Mr Driscoll fell ill, the local authority moved him to a residential care home. Mrs Driscoll was not allowed to go with him, as she did not fit the criteria, and they only saw each other twice a week for 7 months.

Speaking to the media, Beryll said 'We have never been separated in all our years and for it to happen now, when we need each other so much, is so upsetting. I am lost without him – we were a partnership'.

A public campaign launched by the family, supported by the media and various human rights experts, including BIHR, and older people's organisations, argued that the local authority had breached the couple's right to respect for family life (Article 8 of the Human Rights Act 1998 is the right to a private and family life). The authority agreed to reverse its decision and offered the wife a subsidised place so that she could join her husband in the care home.

An example of using the Human Rights Act 1998 to challenge the blanket use of tilt-back chairs in a nursing home.

An NHS nursing home in London had a practice of routinely placing residents in special 'tilt-back' wheelchairs, regardless of their mobility needs. This meant that residents who were able to walk unaided were stopped from doing so. This had a severe impact on their ability to make choices about everyday activities, as well as their capacity to feed themselves and use the bathroom.

A consultant pointed out to staff that their failure to consider the different mobility needs of individual residents was contrary to the principles set out in the Human Rights Act. She drew particular attention to the right to respect for private life (Article 8 of the Human Rights Act 1998 is the right to a private and family life), which emphasises the importance of dignity and autonomy, and the right not to be treated in a degrading way (Article 3 No torture, inhuman or degrading treatment).

As a result the nursing home stopped the blanket practice and residents who could walk were taken out of the chairs and encouraged to maintain their walking skills. Source

<http://www.ourhumanrightsstories.org.uk> Find out more at www.bihr.org.uk

Article 8 of the Human Rights Act 1998 provides a **right** to respect for one's "private and family life, his home and his correspondence"

Article 3 of the Human Rights Act 1998 prohibits torture, and "inhuman or degrading treatment or punishment".



If you have a personal story to share or have any feedback on services you or your family have received, please contact SUF 01473 907087. All our human rights factsheets are available on our website www.suffolkuserforum.co.uk.