

Focus on Dementia and Human Rights Part 2

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 follows on from Part 1 and gives an overview human rights in relation to dementia.

Dementia and Mental Capacity

Dementia is not a disease in itself. Dementia is an 'umbrella term' for a decline in mental ability severe enough to interfere with daily life. Dementia will affect a person's ability to make every day decisions as the condition progresses, and when this happens the person is said to "lack capacity".



Mental Capacity Act 2005

The Mental Capacity Act (MCA) 2005 applies to everyone involved in the care, treatment and support of people aged 16 and over living in England and Wales who are unable to make all or some decisions for themselves. The Mental Capacity Act 2005 must underpin the decision making and advanced planning process for care and family and professionals are fully involved in making decisions about the person's care and treatment. If implemented fully it can support and protect people with dementia who are no longer able to make and communicate decisions



Mental Capacity

To have capacity a person must be able to:

- understand the information that is relevant to the decision they want to make
- retain the information long enough to be able to make the decision
- weigh up the information available to make the decision
- communicate their decision by any possible means, including talking, using sign language, or through simple muscle movements such as blinking an eye or squeezing a hand.

Issues around mental capacity can be complicated, however there is a very helpful, jargon-free Code of Practice available on the gov.uk website that you might find useful.

<https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice>



How is capacity assessed and when does a person with dementia stop making their own decisions ?

It must always be assumed that everyone is able to make a decision for themselves, until it is proven that they cannot.

Generally, families and carers know the person best and so can often tell when the person is and is not able to make a decision.

You can seek advice from others, such as the GP, community nurse, or social worker, if you feel you need to.

It's important that families or carers genuinely believe that the person with dementia cannot make a decision before taking action on their behalf.

The person with dementia continues to have human rights at all stages of the illness

How to communicate with somebody who has advanced dementia:

- Think about the forms of communication you use
- Break information down into small chunks
- Thinking of different ways to describe things

Communication is not just talking, it is body language, facial expressions and gestures.

See the Alzheimer's Society Factsheet: Communicating

www.alzheimers.org.uk



Who can assess capacity?

- For everyday decisions, including what someone will eat or wear, whoever is there at the time can assess capacity, which is likely to be the person's family, carer or care worker.
- For more complex decisions, such as where someone will live, or decisions about treatment, a professional will make the judgment – for example, a social worker or the person's GP. This should be done in consultation with those closest to the person, such as their carer and relatives.

The law says that the only way to establish this is to do a test or assessment to find out whether a person has the ability to make a particular decision at a particular time.

This assessment includes the four criteria listed on page 1 under "Mental Capacity".

Capacity can vary on daily even hourly basis and can be different according to the type of decision to be made. It is about making a particular decision, not about ability to make decisions – capacity varies according to the type of decision, the health at the time, even the time of day can vary the capacity. This requires the need to assess (informally or formally) capacity for each decision - one should not make blanket assumptions.

The Deprivation of Liberty Safeguards (DoLS) are part of the Mental Capacity Act 2005. They aim to make sure that people in care homes, hospitals and supported living are looked after in a way that does not inappropriately restrict their freedom.

What is deprivation of liberty?

There is no specific definition of deprivation of liberty in the Mental Capacity Act 2005. However, it must encompass the definition set down in Article 5 of the European Convention on Human Rights (ECHR) and related case law.

Whether someone has been deprived of their liberty depends on the particular circumstances of each case.

The Code of Practice accompanying the safeguards states:

The difference between deprivation of liberty and restriction upon liberty is one of degree or intensity. It may therefore be helpful to envisage a scale, which moves from 'restraint' or 'restriction' to 'deprivation of liberty'.

<http://www.ageuk.org.uk/>

Power of Attorney

There are a number of reasons why you might need someone to make decisions for you or act on your behalf.

It could just be temporary: for example, if you are in hospital and need help with everyday things such as making sure that bills are paid. Or you may need to make more long-term plans if, for example, you have been diagnosed with dementia.

Lasting Power of Attorney (LPA) is a legal tool that allows the person to appoint someone to make certain decisions on their behalf.

For more information about power of attorney visit

<http://www.ageuk.org.uk/>

Sometimes, caring for a person with dementia involves reducing their independence or restricting their free will in some way.



If the person with dementia is receiving care in a hospital or care home, their routine may be decided for them, and they may not be allowed to leave. If the person has not freely chosen where they will live in order to receive care, or the type of care that they receive, it is possible that this care will take away some of their freedom. In some cases, this may amount to a 'deprivation of liberty'.

This is not always a bad thing, and it is often necessary when caring for someone, but it should only happen if it is in the person's "best interests" – continued on page 4

Focus on Dementia and Human Rights

What does “Best Interests” mean?

It is important for the application of the Mental Capacity Act to have a fundamental understanding of the “best interests” principle.

If a person has been assessed as lacking capacity then any action taken, or any decision made for, or on behalf of that person, must be made in his or her 'best interests' (known as principle 4).

Some of the factors that are taken into consideration are:

- Do not discriminate. Do not make assumptions about someone’s best interests merely on the basis of the person’s age or appearance, condition or any aspect their behaviour.
- Take into account all relevant circumstances
- If faced with a particularly difficult or contentious decision, it is recommended that practitioners adopt a ‘balance sheet’ approach
- Will the person regain capacity? If so, can the decision wait?
- Involve the individual as fully as possible
- Take into account the individual’s past and present wishes and feelings, and any beliefs and values likely to have a bearing on the decision
- Consult as far and as widely as possible.

MyBrainBook

MyBrainBook puts people with dementia at the centre of decisions about their care. It is a personalized online tool delivering facilitated support to people with dementia, their carers and family. While MyBrainBook enables your doctor or social care worker to understand you and your needs better, loved ones can also login and keep in touch with you through an online chat facility.

<http://mybrainbook.com/>



“This is me tool” A tool for people with dementia to complete that lets health and social care professionals know about their needs, interests, preferences, likes and dislikes. It is a printable leaflet that contains information such as “name I like to be called” and will support a person in an unfamiliar place

https://www.alzheimers.org.uk/site/scripts/download_info.php?download

SUF Mental Health Advocacy

I know I have rights, choices and a voice

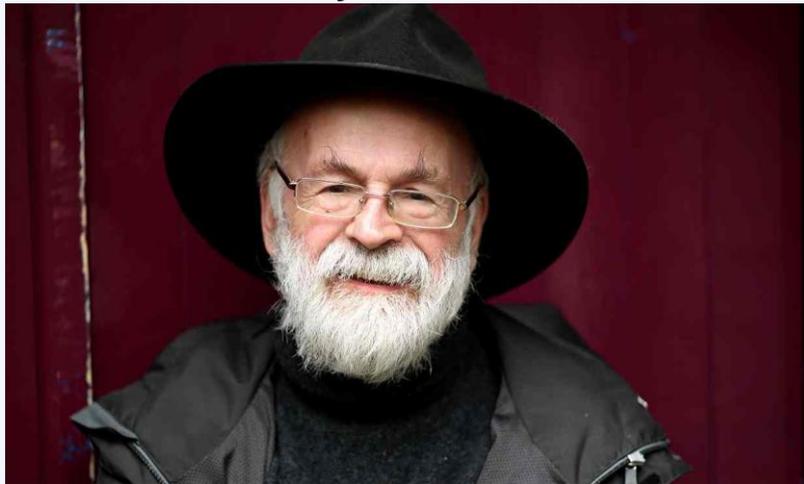
James Woolnough has recently joined SUF as our Mental Health Advocate. James can be contacted by email Advocacy@suffolkuserforum.co.uk



www.suffolkuserforum.co.uk

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.

‘A butt of my own jokes’: Terry Pratchett on the disease that finally claimed him



When I look back now, I suspect there may be some truth in the speculation that dementia (of which Alzheimer's is the most common form) may be present in the body for quite some time before it is capable of diagnosis.

For me, things came to a head in the late summer of 2007. My typing had been getting progressively worse and my spelling had become erratic. I grew to recognise what I came to call Clapham Junction days, when demands of the office just grew too much to deal with. I was initially diagnosed not with Alzheimer's but with an ischaemic change, a simple loss of brain cells due to normal ageing. That satisfied me until the next Clapham Junction day. I went back to my GP and said that I knew there was something more going on.

Fortunately she knew well enough not to bother with the frankly pathetic mini-mental state examination and sent me to Addenbrooke's Hospital, Cambridge, when, after examination of my MRI scan and an afternoon of complex testing, I was diagnosed with PCA – an uncommon variant which had escaped the eagle eyes of the original diagnostician.

“I feel very sorry for, and angry on behalf of, the people who don't have the easy ride I had. It is astonishing how long it takes some people to get diagnosed (they write to me). I cannot help but wonder if this is because doctors are sometimes reluctant to give the patient the stigma of dementia, since there is no cure.”

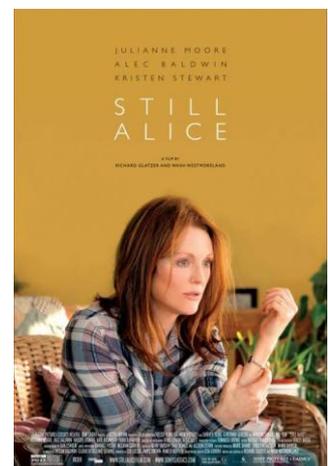
<http://www.theguardian.com/books/2015/mar/15/a-butt-of-my-own-jokes-terry-pratchett-on-the-disease-that-finally-claimed-him>

Films

“**Still Alice**” is a 2014 film that portrays a woman diagnosed with Alzheimer's aged 50, Janet Baylis.

“**Away from her**” is a 2006 film about a man coping with the institutionalization of his wife because of Alzheimer's.

“**Iris – A memoir of Iris Murdoch**” is a 2001 biographical drama film that tells the story of Irish novelist Iris Murdoch and her relationship with her husband John Bayley as her Alzheimer's progresses.



Suffolk Family Carers aim to improve the lives of family carers and the person they care for by providing them with information and advice that can help support them in their caring role. Call their **Information Line 01473 835477** to register yourself as a family carer to start accessing some support.

Find out more about the *Caring for Dementia with Confidence* programmes



<http://www.suffolkfamilycarers.org/>



Debenham project

<http://www.the-debenham-project.org.uk/>

The "Debenham Project" is a community owned and led project in the village of Debenham, central Suffolk. Since its formal launch in October 2009 local volunteers have developed a range of local dementia support services. Debenham has become the UK's foremost rural "Dementia Friendly Community." Our aim is to help all those families in our area who are having to cope with the impact of dementia on their lives - to offer them the practical and emotional support which can make "living with dementia" a better place than when they were "on their own" - to show that that their community cares and wants to support them in their difficulties - and that there are those around them that have "been there" and understand the problems and emotions that they are going through.

Age UK Suffolk offer day services at Ipswich, Bury St Edmunds, and Sudbury.

Day services and centres offer support for older people who live within the local community.

<http://www.ageuk.org.uk/>

"A diagnosis is not the beginning of the end, you can live well with dementia"



Memory Services National Accreditation Programme (MSNAP)



Sue Parker became involved with the Royal College of Psychiatrists through being part of SUF several years ago. Sue tells us

"The lack of a consistent model means that the quality and characteristics of memory services can vary greatly across a county and across the country. The Royal College of Psychiatrists have the Memory Services National Accreditation Programme (MSNAP) to develop a set of standards for memory services."

"This is a voluntary accreditation programme and its primary aim is to support organizations to deliver better services. There is service user and carer involvement and feedback as part of the assessment. Unfortunately Suffolk has not signed up to MSNAP and I feel this is a great pity and an opportunity lost"

Equality, discrimination and human rights



People with dementia and carers should be treated with dignity and receive care and support that is based on individual need, rather than assumptions about the condition. In the community, the contribution of people with dementia should be valued.

Too often, people with dementia experience discrimination and treatment that contravenes their human rights. Poor care and support can breach the rights of people with dementia and carers to not be treated in an inhuman or degrading way, the right to respect for private and family life and the right to liberty.

People with dementia can face discrimination and treatment that contravenes their human rights for three key reasons:

- *Ageism*
- *The stigma and discrimination associated with the condition*
- *Lack of capacity to challenge and report incidents that occur*

Find out more at www.bihhr.org.uk



Legal Advice Support

The Suffolk Law Advice Centre provides 30 minutes free legal advice, from local legal professionals, to anyone who lives or works in Suffolk, regardless of their means, or ethnic group.

Their volunteer lawyers run specialist clinics in family, housing, immigration, employment and personal injury law as well as two general clinics each month.

To arrange an appointment email lawadvicecentre@iscre.org.uk

or call 01473 408111.

<http://www.iscre.org.uk/legal-services/suffolk-law-advice-centre/>

Older People and Human Rights

Absolute/non-absolute rights

Some rights are known as 'absolute' rights. This means they can never be limited or restricted under any circumstances. Other rights are non-absolute (e.g. they are limited or qualified) and may be limited or restricted under certain conditions, such as to protect the rights of others or the wider community. The conditions under which they can be limited or restricted are specified in the article that sets out the right.

Right to respect for private life; Right not to be treated in an inhuman or degrading way; Right to life.

Case study

Mrs S, aged 102, felt isolated, disrespected and neglected while she was in hospital. Despite being blind, her meals and drinks were left on a trolley – in most cases without her being alerted. For the most part, staff also did not offer any assistance with eating or drinking. As a result, many of the meals were removed untouched. Mrs S also suffered a great indignity when she asked for a commode, but was told by a nurse that she could use her incontinence pad. Staff frequently talked over her and about her rather than to her in the mistaken belief that she was unable to talk for herself.

Source: Age Concern (2008) On the Right Track?

Case study

A consultant came across an older woman on a hospital ward in London who was crying out in distress. The woman was in a wheelchair and when the consultant lifted up her blanket, she discovered that the woman had been strapped in and that this was why she was so upset. Staff explained that they had fastened her into the wheelchair in order to stop her walking around because they were fearful she might fall over and hurt herself. The consultant told staff that while their concerns were understandable, strapping her into a wheelchair for long periods was an inappropriate response because her human rights had not been taken into account. She pointed out that this could be considered degrading treatment (Article 3) given the impact on the woman. Staff quickly agreed to unstrap her and, after she was assessed by a physiotherapist, they were encouraged to support her to improve her mobility.

Source: BIHR (2008), The Human Rights Act – Changing lives, 2nd edition

My Fundamental human rights ...

... How I can say "*I am me &*

how I choose to express myself!"

1. I have the right to state my own needs and set my priorities as a person, independent of any roles that I may assume in my life.

See the full list of Human Rights at www.suffolkuserforum.co.uk