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Wellbeing for Life

The Emotional Impact of Dementia

Learning Outcomes

- To have an understanding of the emotional impact on the person with dementia, their peers, friends and workmates, their family and the staff who support them.
- To be aware of the range of emotions experienced as a direct result of a diagnosis of dementia and living with dementia.
- To have practical tips on supporting someone with dementia, their friends and family.
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- To look after your own emotional wellbeing in order to support someone with dementia.

Dementia:
An Emotional Rollercoaster

Of all the elements associated with dementia care and support, the emotional aspects are amongst the most challenging for the person with dementia and their circle of support (their friends, peers and workmates, their family and their staff team).

We all experience emotions differently. Some people naturally openly express their emotions, whether they are happy or sad.

Other people may hardly show any emotion at all, although this doesn’t necessarily mean that the person isn’t just as emotionally affected as someone who is openly crying or angry.

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Dementia:
An Emotional Rollercoaster

There is no right or wrong in respect of the emotions a person feels or the way in which they do, or don’t, express those emotions. All emotions should be acknowledged and validated.

Most people will live with their type of dementia for many years, and emotions are likely to fluctuate considerably over that time for the person with dementia and everyone involved in their life, so it’s helpful to be prepared to cope with this emotional rollercoaster.

Everyone should be encouraged to express and share their emotions. Finding ways to manage emotions is important to ensure that they do not become overwhelming and negatively impact upon any individual’s health and wellbeing.

Dementia:
An Emotional Rollercoaster

Remember: Everyone will be trying to manage their own emotions as well as the emotions of others, so be kind.

While the emotional side of dementia care and support can be difficult to deal with, it’s important to also appreciate the rewards that come with providing dementia care and support.

Whilst your role may be physical and mentally demanding, there are also opportunities to participate in wonderful moments of shared time that are precious and priceless. These positive aspects can provide strength and hope in difficult times.

The Emotional Impact on the Person with Dementia

As a society, we are able to learn a lot from people who have dementia about how they experience the emotional impact of dementia.

Although it's important to remember that everyone is a unique individual, some of the common themes that people with dementia talk about in relation to the emotional impact upon them include:

- The range of emotions they have felt in relation to their diagnosis and the implications of having dementia – for example grief, loss, shock, denial, anger, fear, disbelief or relief.
- The way in which the damage to their brain from their type of dementia has affected their emotions – for example making the person more tearful or angrier.

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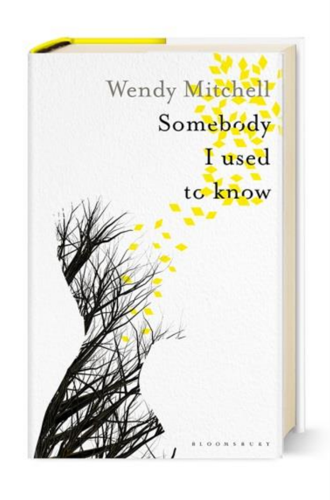
The Emotional Impact on the Person with Dementia

- The way in which day-to-day and life events have come into a sharper emotional focus – for example feeling frustration at not being able to do something or find something, or not being able to remember that a loved one has died.
- Feeling 'out of control' with your emotions – for example feeling like you can't stop crying, or can't stop lashing out.



"Every day is different. Some days it feels like Alzheimer's has never entered my life and some parts of some days are like this too. On bad days, it's like a fog descends on the brain and confusion reigns from the minute I wake up. On these days it feels like there's so little in the brain left to help you get through the day**.**"

- Wendy Mitchell, lady living with dementia
https://whichmeamitoday.wordpress.com/2015/03/18/what-does-dementia-feel-like/

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The Emotional Impact When you have a Learning Disability and Dementia

It can sometimes be difficult for people with a learning disability to communicate exactly how they feel about having a diagnosis of dementia. Often we only learn about how the person is feeling emotionally through their behaviours.

It is sadly a reflection of attitudes and untimely diagnosis that people with a learning disability may not be told they have dementia before they lose capacity to understand what it means.

And remember that some people with a learning disability are never told that they have dementia, or ultimately are not diagnosed by a Health Professional, as a GP *may* see the learning disability first, and not the dementia.

The Emotional Impact When you have a Learning Disability and Dementia

Not having all the information doesn’t mean that the person doesn’t experience the same range of emotions, instead they might respond to the practical impact of dementia on their day-to-day life rather than any understanding of the longer-term implications of dementia.

It is our job to make sure the person understands their diagnosis, in a way that makes sense to them (if they want to know and have capacity to understand).

The Emotional Impact When you have a Learning Disability and Dementia

- People react in different ways to a diagnosis, a few examples include; If the person has been told their diagnosis they may experience increased emotions that are triggered by the changes and loss in what they used to be able to do.

- The person may experience depression or anxiety as a reaction to the changes in their life caused by their dementia.

- Due to the damage caused in their brain by dementia, the person may no longer be able to control their own feelings or how they express them.

What Can you do to Help?

You are in a unique and privileged position to support the person with the emotional impact of their dementia. Ways you can do this include:

- Seeing things from the person's perspective – how would you feel?
- Look beyond words and behaviours – what is the person telling you? What do they need from you? For more information, please see our Module or e-Booklet on 'Changed Behaviours' in Theme 5 The Dementia Pathway
- Be informed - remember that dementia causes damage to the person's brain, what they may be doing isn't to deliberately upset or annoy you.
- Support the person to express their emotions – this doesn't have to be with words, consider music or art as a way of expressing and managing emotions.
- Listen carefully and do not dismiss the person's emotions – the emotions they feel are very real to them even if they have little control over them or how they express them.

What Can you do to Help?

- Help the person manage their emotions, especially if they are unable to stop a particular emotion (for example sadness and crying). Once you have acknowledged their emotion and understood why they are feeling this way, you may need to distract them by doing something else in order to get their emotion under control and move on. Remember though that this is never about ignoring how someone is feeling.

- Give the person plenty of time to respond or complete a task – a time pressure increases stress which causes a negative emotional response.

- Give encouragement, reassurance and guidance in a way that makes sense to the person.

- Support the person to make lifestyle changes to reduce the impact dementia has on their independence and day to day life. For more information, please see our Module or e-Booklet on ‘Promoting Independence and Safety’ in Theme 4 Good Support

- Find out what non-pharmacological treatments are available and support the person to try them. For more information, please see our Module or e-Booklet on ‘Treatments’ in Theme 5 The Dementia Pathway

The Emotional Impact of Dementia on Friends, Peers and Work Mates

The emotional impact on the friends of people with a learning disability and dementia can be ignored, forgotten or minimised. It can be very difficult for others to manage their emotions when they see their friend behaving in a totally different way to how they have in the past.

Friends, peers and work mates may experience this as a loss of:

- Their relationship
- The special understanding they had together
- Communication
- Shared hobbies
- Shared lifestyle

They may experience emotions related to:

- Having to take on more responsibility
- Being depended on

The Emotional Impact of Dementia on Friends, Peers and Work Mates

***Some* of the emotions that may be felt are:**

- **Sadness** – at the loss
- **Frustration** – that the person doesn't do things with them any more
- **Annoyance** – that they do things differently to how they have before
- **Anger** – at the person for changing, at themselves for not knowing what to do
- **Pride** – at being able to help their friend
- **Satisfaction** – continuing to be their friend
- **Resentment** – at the changes and "attention" the person now gets from more staff support
- **Fear** – of the person becoming very ill and dying, especially if they have a bereavement fresh in their mind

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The Emotional Impact of Dementia on Friends, Peers and Work Mates

These emotions may be expressed in the way they behave:

- Shouting at the person
- Pushing the person away
- Ignoring the person
- Taking over doing everything
- Sulking and withdrawing
- Refusal to do things with the person

For more information, please see our Module or e-Booklet on ‘Supporting Peers and Friends’ in Theme 5 The Dementia Pathway

What Can you do to Help?

Recognising the important role of friends, peers and workmates in the person’s life, and finding ways to support everyone will help relationships to be maintained and to flourish.

Ways to do this include:

- Spend time talking to friends, peers and workmates, either together or in groups – choose a suitable time and pace, and support their understanding about what is happening by using language, pictures, guides that are clear and free from jargon. Help them to acknowledge and accept their emotions and find ways to cope with how they are feeling.

- Keep lines of communication open – find opportunities in everyday life to keep conversations going with friends, peers and workmates, rather than scheduling a specific time to discuss dementia which could make everyone feel uncomfortable and on-edge.

What Can you do to Help?

- Focus on the positive and what they can still do with the person who is living with dementia.

- Support them to help their friend, peer or work mate – you may find the best way to do this is through role modelling ways they can support the person with dementia.

- Make sure everyone has their own time to do things they enjoy – having a friend, peer or work mate with dementia shouldn't mean that all the focus is on the person with dementia.

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The Emotional Impact on Family

Dementia can have a significant impact on the family of the person who has been diagnosed. Coming to terms with a loved one’s diagnosis of dementia and the implications for the future will produce a whole range of emotional responses from family members, some of which may be difficult for you to understand or frustrating to cope with.

You must always be mindful, however, that supporting family members to the very best of your ability is an important part of your role, regardless of whether you agree with them or not.

Because people with a learning disability are often diagnosed younger than people who don’t have a learning disability, it may be a huge shock to family members if they only associate dementia with the traditional, but incorrect, viewpoint that dementia is only something older people develop. For this reason, a diagnosis may be at best unexpected, and in some instances not believed.

The Emotional Impact on Family

Finding out that someone you love has a terminal diagnosis is not something any of us are necessarily prepared for, and the idea that an adult child could die before their parents is something ageing parents may find particularly hard to come to terms with.

In addition, if the person’s diagnosis has come quite late, their dementia may be progressing rapidly, giving family little time to adjust or come to terms with the news.

Some families may find themselves in a situation where their adult relative is becoming independent and considering moving out of the family home, only to be diagnosed with dementia at a young age.

Equally, parents and siblings will be ageing themselves and possibly making plans for their retirement, only to now find themselves as family carers for a relative who has a learning disability and dementia.

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The Emotional Impact on Family

If the person lives in the family home and the family are struggling to cope, they may feel huge guilt if the person has to move into a residential care service.

If the person is already living in a residential care service or accessing lifelong learning, family members may become concerned that their loved one will have to leave a service they've been very happy with following their diagnosis of dementia or if their relative's dementia has advanced.

Remember, leaving a service once a person is in the advanced stages of dementia is not necessarily what is best for the person – as a team, you need to trust your judgement, and liaise with the person and their family on where is best for the person at their end stages of life.

Whilst the person had capacity, did the team work together to create an Advance Care Plan? This is important for each and every single person that we support, we never know what tomorrow will bring, so having an Advance Care Plan (that is regularly updated if preferences or wishes change) in place creates peace of mind that their wishes are respected and followed at the end stage of life.

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What Can you do to Help?

It’s important to remember that family members, peers, friends and work mates of a person with dementia will find themselves adapting to a constantly changing situation that they are most likely ill-prepared to cope with; they don’t have the benefit of the professional development that social care staff have.

They will have their own emotional responses to the person's dementia as well as supporting the person with dementia with their emotions.

They have to balance supporting the person's emotional needs with their own which can be very difficult. Personal relationships and friendships may also cause additional challenges.

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What Can you do to Help?

Ways you can help to support:

- Listen to the concerns that are brought to your attention and be sensitive to their emotions.
- Signpost people to further information and advice from professionals, including easy read information or training opportunities if these exist in their location.
- If the person diagnosed is a younger person, signpost people to resources specifically about younger onset dementia – Young Dementia UK https://www.youngdementiauk.org/
- Suggest they meet other carers and families of people with dementia – ways to do this include local carer support groups and national peer support networks. – TIDE http://tide.uk.net/

tide™
together in dementia everyday

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What Can you do to Help?

Ways you can help to support:

- Involve them as much as they want in all aspects of the care and support you are providing for the person.

- Support the person to maintain contact with their family – families often drift away, or become split, sometimes because family members do not know how to interact with their loved one now they have dementia. If family members want some tips or advice, use your knowledge to help them, or ask for help if you are not sure.

- Look out for local events, for example MacIntyre have their own Memory Cafès in Warrington and Milton Keynes that are aimed at families, staff and the people living with dementia. If you do not have a local event in your area, why not create one? The Dementia Project team at MacIntyre are always happy to help people start their own Memory Cafes or keen to listen to new ideas.

The Emotional Impact on the Staff and Team

Whilst staff are often told to maintain professionalism and not get emotionally involved with the people they are providing care and support for, in reality the very nature of social care and the skills staff are recruited for, like compassion and empathy, naturally mean that as human beings staff will feel strong emotional responses.

Some of the emotions experienced in relation to a person you support being diagnosed with dementia may include:

- Grief for the diagnosis and future losses that will occur
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- Loss of the relationship you had with the person

- Loss of a shared understanding and communication

- Loss of the shared things you did together

The Emotional Impact on the Staff and Team

Acknowledging your emotions, and not feeling ashamed of them, is important for your own mental health and wellbeing.

Whilst you should never be openly emotional with a person you are supporting if that is likely to cause them additional stress or anxiety, discussing your feelings with colleagues, your line manager, or having reflective sessions as a staff team during team meetings are all important ways to help release emotions, ensuring colleagues know that they are not isolated by their emotions and helping everyone to cope better.

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Ten Top Tips for Staff to Build Emotional Resilience

1. Don’t be hard on yourself – you are a human first and a social care professional second.

2. Be aware of how the person’s dementia diagnosis impacts upon the person – keeping the person at the centre in your thinking will help you to focus on what they need.

3. Acknowledge the way the person’s dementia diagnosis will change your role and the way you support the person – embrace this rather than denying it.

4. Realise that the person may not show their appreciation of you in the same way they have previously, or their appreciation of you may appear to diminish – this is not deliberate.

5. Seek out knowledge –look to upskill yourself, the more you know about dementia, the better equipped you will feel to support the person.

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Ten Top Tips for Staff to Build Emotional Resilience

6. Organise yourself - recognise conflicting demands and prioritise to help you provide the best support you can to everyone who needs you.

7. Live in the moment – be adaptable and ready to change your approach to match what the person needs right now.

8. Know your own limits – talk to your colleagues and manager if you are feeling out of your depth.

9. Don’t get overwhelmed - recognise when you need a break.

10. Think about your own health and wellbeing - eat healthily, keep hydrated with plenty of water and incorporate regular exercise that you enjoy into your life. For more information, please see our Module or e-Booklet on ‘Wellbeing’ in Theme 1 Fit for the Future

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