



Wellbeing for Life

The Emotional Impact of Dementia on Everyone: Supporting Peers and Friends



Learning Outcomes

- Being aware of who may be affected by the person's diagnosis of dementia.
- Considering a person's choice and wishes for who they would like to know about their diagnosis, including where Best Interest Decisions need to be made.
- Practical tips on how to include and involve everyone.



Dementia Affects Everyone

When you live in a house with other people, go to social groups or to work, you form relationships – sometimes close friendships – with the people who you share your time and space.

Dementia affects relationships because it creates uncertainty, produces symptoms that can be upsetting for everyone, and means that changes are happening now - and are going to continue to happen in the future - that will affect the person and everyone they are close to.

To **love** a person is to
see all of their magic,
and to remind them
of it when they have
forgotten. ❤️

Friendships and Dementia: The Statistics



From the Alzheimer's Society Dementia 2012 report:

https://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=821

“The survey shows that respondents reported losing friends after their diagnosis or being unable to tell them. Nearly half (44%) of respondents said they had either lost most of their friends, some of their friends, or hadn't been able to tell them.”



When Dementia is Suspected

When a person is developing dementia, it is likely to be a difficult time for the person, their peers and friends and the staff supporting them.

The changes associated with dementia can be complex and may seem baffling to everyone until a formal diagnosis is made.

Being mindful of everyone's feelings, emotions and the adjustments that are happening in their relationships is vital.

Before a diagnosis of dementia is made it is important for you to consider the implications of a diagnosis of dementia for a person before a diagnosis is made. By planning in this way and talking to the person undergoing the dementia assessment you can encourage them to think about their needs and wishes.

Key questions include whether the person wants to know their diagnosis when it is made, and if they want anyone else to be told.



If the person wants other people to know, who are those people and how should they be informed?

When there is uncertainty about consent to share information.

If health professionals, or support staff, are unsure about whether the person can consent to details of their diagnosis being shared, they should refer to the Mental Capacity Act and Best Interests Decisions.

Confidentiality is vitally important and correct protocols, as set out by the law and the organisation you represent, must be followed.



After a Diagnosis of Dementia

- If the person wants their peers and friends to know about their diagnosis, you will need to support the person to decide if they want to give that information themselves, or if they want you to lead those interactions.
- Where you are informing peers and friends about a person's dementia diagnosis, this needs to be done sensitively and in a dignified and respectful way.
- You may need to carefully plan how this is done, and be prepared to introduce information in stages and to repeat information as needed.
- There is no specific duration for this – it may take minutes, hours, days, weeks or months.



Acceptance of a Diagnosis

Some people view a diagnosis of dementia as a relief because it explains what is happening to the person.

Other people have more questions than answers after a diagnosis and may struggle to come to terms with this new reality that they, or someone they are close to, is experiencing.

Within a household or group of peers or friends, you can expect to see many different reactions. These are unique to each individual, and require you to help each person navigate their way through what they are feeling.





Coping with the Fears associated with Dementia

- When supporting a person who is diagnosed with dementia to inform their peers and friends, you need to be calm, reassuring and be confident in having up-to-date knowledge of dementia.
- You may be feeling emotional yourself, but you should never allow your own feelings to project onto the people you support.
- At all times you should avoid using stigmatising language or giving information that is misinformed or misguided.
- Many people associate a sense of loss with dementia, and in more acute situations, feel grief even though the person is alive. You should be aware of these emotional responses and be prepared to deal with them in a compassionate way.



Explaining Dementia

The MacIntyre easy read resources to explain 'What is dementia' offers a format that is designed to explain dementia to a person with a learning disability.

The leaflets explains to the person what the brain does, what dementia is, what can happen, how the person may feel and what you can do to help the person with dementia.

It is important to remember that you are likely to need to use this resource differently with different people. Some people may want to know all of the available information, whilst others may only want to know some of it, and others may reject the information completely.



Dealing with Denial

- Despite the best efforts of support staff and health professionals to explain a dementia diagnosis, the person who has been diagnosed may not understand their diagnosis.
- Equally some of their peers or friends may not understand either.
- Depending on how advanced the person's dementia is their brain may be unable to comprehend what a diagnosis of dementia means.
- Equally, peers or friends with severe or profound learning disability may be unable to fully appreciate what dementia is and what a diagnosis means.
- Whilst denial may frustrate you, it is important to remember that everyone has their own way of coping with life-changing news.
- **There is no right or wrong.**



Day-to-day Life

- Whilst dementia inevitably changes many things in a person's life, trying to keep day-to-day routines as regular as possible for everyone is usually the most positive approach.
- Creating a big fuss around a person who is diagnosed could make them feel 'singled out' in an unhelpful way, or make their peers and friends feel 'left out'. You need to find the right balance using your experience of all the people involved.
- Where extra help or support is needed for the person with dementia, you should use your judgement and knowledge of the people you support to make sure you get the balance right between meeting the needs of the person with dementia and ensuring their peers and friends have equal access to the support that they need.



How Peers and Friends can help the Person with Dementia

Concerned and caring peers and friends may want to help the person with dementia. Practical help should be encouraged and supported – it is likely to be beneficial for all concerned.

Think about the best ways that peers and friends can support the person with dementia.

Ideas include:

- Helping the person to maintain hobbies or activities that they enjoy.
- Bringing fun and laughter into their life through shared interests like sports or music.
- Attending events together to provide mutual companionship.
- Sharing special meals, celebrations or trips out together.
- Reminiscing with the person through the creation and/or use of life story resources.



As a Person's Dementia Progresses...

- Given that dementia is progressive and terminal, the person is likely to deteriorate. This will happen in different ways and within different timescales for each person.
- Peers and friends may find deterioration even more upsetting than the initial diagnosis, and you need to use your judgement as to how much peers and friends can cope with seeing and experiencing before their own quality of life is impacted.
- Where there are concerns about how peers and friends are coping, you need to consider what is in their best interests, and how to structure and support the time peers and friends spend with the person who has dementia.
- Making small changes to the time and space people have to interact with each other may be all that is needed to help everyone enjoy their time together again.



Maintaining Friendships throughout a Person's Dementia

- Dementia is known to be a very isolating condition; as a person deteriorates that isolation often increases.
- Helping a person to maintain contact and quality time with their peers and friends is vitally important.
- If the person with dementia needs to move to different accommodation, you should encourage peers and friends to keep in touch through visits, sharing hobbies and activities, attending events like birthday parties or exchanging cards or gifts.
- Peers and friends might also like to use digital technology to keep in touch - ways to do this include making films about shared interests that can become part of the person's life story resources, and sending emails and photos with news.

Interacting with a Person with Advanced Dementia

You will need to be creative in how you encourage peers and friends to interact with a person who has advanced dementia.

If the person is quite frail, think about activities that are soothing.

Ideas include:

- Stroking hands or holding hands
- Singing with the person





Interacting with a Person with Advanced Dementia

Ideas include:

- Talking about shared interests, e.g. sports, music or films
- Looking at photos together
- Watching TV or having a 'movie night' and watching a favourite film together
- Helping with practical tasks, like making the person comfortable in their chair or bed, or making them a drink or some food that they enjoy.



When Peers and Friends are Struggling to Cope

- It is possible that peers and friends may find it difficult and eventually impossible to cope with seeing someone they care about living with dementia.
- If they no longer want to have contact with that person, their decision has to be respected and you will need to support them to continue their life in whatever way makes sense to them.
- You need to think about how you provide additional support to the person with dementia in this situation to reduce any distress that they may feel.

**ONLY THOSE
WHO CARE
ABOUT YOU
CAN HEAR
YOU WHEN
YOU'RE
QUIET.**



Qualities Staff Need to Show

- It is important throughout a person's dementia, from pre-diagnosis to end-of-life, that you are sensitive to the many emotions that accompany dementia for everyone whose lives are touched by it.
- Qualities you will need to demonstrate include being non-judgemental, adaptable, creative, understanding and reassuring.
- All staff involved in supporting the person with dementia, their peers and friends, should work together as a team to help every person being supported to maintain their relationships in whatever ways they are comfortable with and for as long as they want.



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<https://www.bethbritton.com/>

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602 South Seventh Street
Central Milton Keynes
MK9 2JA
www.macintyrecharity.org