Let’s talk about dementia: starting your own conversation

For more information on dementia and the support available to you, visit: www.alzscot.org

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Introduction

This leaflet is designed primarily for family members, partners and friends who are concerned about someone who they think might have dementia, and how to start a conversation around this. However, if you are worried about symptoms you are experiencing yourself, there is information further on in this leaflet on where you can access support.

Your early conversations about signs which might indicate dementia are often very difficult as the person’s reaction to your first raising the topic can be unpredictable. There may be relief at being able to talk to someone about their worries, however there could also be a refusal to discuss, anger, distress or a denial of any change. We all experience things differently and reactions will vary but hopefully, over time, talking will get easier and you will all be able to agree on the best way forward.

Changes in dementia are often subtle at first and may be experienced as differences in your relationship rather than obvious features of illness.

Examples of changes may include:
- Changes in behaviour and ‘out of character’ responses to situations
- Less interest in regular activities
- A loss in confidence or ability in areas that previously posed no difficulty
- Difficulty in planning or ability to make decisions
- Confusion over seemingly easy day-to-day tasks, such as cooking or handling money
- Challenges in finding the correct words or holding a conversation.

We’ve always been so close and he seemed so different towards me that at first I thought he didn’t love me anymore

Sam speaking about his partner Bob and concerns before Bob’s diagnosis.

Changes of such a nature can also be associated with many other health conditions and stressful situations. It’s vital to seek medical advice early to identify the cause of the changes. The process of identifying dementia involves ruling out other possible explanations. There may be effective treatment or management options to explore with a medical professional. Whether the concerns are associated with dementia or not, there are many advantages in early identification.
Approaching the conversation

It may take more than one conversation to address the concerns you have around your friend or family member and the possibility they may have dementia. Whilst it’s useful to think about what you want to say in advance, sometimes opportunities may arise in natural conversation when the person you’re concerned about indicates in some way that they too have concerns. The nature and strengths of your relationship will inform how you might best approach this conversation. Spiritual and cultural aspects may also be influencing factors in how you both approach and respond to the fears you may have.

There is no set approach to having these conversations but the considerations below may be helpful:

• Try to find a time when you’re both in a relaxed, mutually comfortable environment and not already feeling tired or stressed
• Allow time for the conversation, it shouldn’t be rushed
• If possible, spend time before the conversation thinking about what you want to say.
• The person you’re speaking with may be feeling anxious or vulnerable, so the conversation should be as informal as possible and avoid any element of confrontation
• You may want to explore with the person how they’re feeling about their health before mentioning your concerns. They may already be aware of symptoms and changes in themselves but are not quite ready to share these. Give them time to talk about how they feel, as they may be worried about things like:
  » How others will view them
  » Losing control over their lives and future decision making
  » Their future in general.
• It might be beneficial to focus more on the symptoms instead of assumptions about the causes or potential diagnosis, unless anything specific is raised by the person concerned
• Think about how you would feel if you were in the person’s shoes. Although you may be anxious, try to be sensitive as to how the person themselves may be feeling.
Next steps

Once your conversation has opened up communications around concerns, it is good to consider what the next steps might be. This will be a daunting time for you all, and especially the person you’re concerned about.

- It might help to talk through in advance how you might approach this with someone who can offer support and information. You could contact our 24 hour Freephone Dementia Helpline (0808 808 3000) or access local support - details of which are available on our website: www.alzscot.org
- Continue to have open conversations that build trust and confidence in talking about problems experienced
- Ask the person how they want to move forward and look to arrange an appointment with a GP. You can request a joint appointment at a GP practice, with the person’s consent and can also ask for a longer appointment so you have time for an in-depth conversation
- Once you have an appointment, consider writing down your concerns so you have something to refer to during the conversation
- Look at other support; Alzheimer Scotland provides a range of support which can begin prior to a potential diagnosis of dementia.

If the person you’re concerned for does not want to see their GP, you could book an appointment for your own GP. They won’t be able to discuss this person due to confidentiality, but they will be able to give you some guidance around this.

Whilst this can often be a stressful time, if your relative, friend or partner does have dementia then early diagnosis is key. It gives you all the best opportunity to learn about the illness, how to manage symptoms and make plans for the future. It will also open up the door to the wide range of support that is available, including at least one year’s guaranteed post-diagnostic support.

What to do if you’re concerned about yourself

If you are concerned about changes and symptoms you are aware of in yourself, we would encourage you to share your concerns with someone you trust - this could be family, friends or your local GP. We are all different and you will know who you would feel most comfortable speaking to in the first instance. An early approach to your GP provides the best opportunity to identify the cause of your symptoms (which may or may not be dementia), manage these with any available treatment and discuss your options. It’s important that you feel supported throughout this process and Alzheimer Scotland’s 24 hour Freephone Dementia Helpline is available 365 days a year to provide information and emotional support. If it is dementia, there is still much that can be done to support you to manage things for yourself and continue to engage in the things you enjoy.