



Information for parents on supporting children affected by dementia

Introduction

There will be an estimated 1m people living with dementia in the UK by 2021. Dementia has an impact on the whole family, including children. Children may see changes occurring in their relative and not understand what is happening, or feel able to talk about it.

In September 2018, Dementia UK developed a short animation film, 'Let's talk about dementia', to help raise awareness about dementia among children, and help them start conversations about dementia and share their personal experiences.

Parents have found the animation helpful and as a result requested further information about the condition and how best to support their children. The links to the resources below aim to support parents and other adults involved in caring for children affected by dementia.



1. Where can I find information on dementia for children?

Dementia UK provides a variety of information about dementia. There is a dedicated page on the Dementia UK website which is designed to explain dementia to young people.

www.dementiauk.org/youngpeople

The page features a short animation, which can help to initiate conversations about dementia and how children might feel if they have someone with dementia in their family.

For older children, teenagers and young adults, there are six short films about young people's experience of supporting someone with dementia in their family.

The page features an infographic of advice and tips for young people on communicating with someone with dementia.

2. How can parents best support their children when they have a relative with dementia?

Children who have a relative with dementia may express their feelings and emotions in different ways and you may notice some changes in their behaviour. They may become quiet and withdrawn, act out of character or their school work may be affected, as seeing changes in someone they love may be very unsettling.

If you are a carer for someone with dementia, your child(ren) may be worried about you, or it may be affecting family relationships. Caring for someone with dementia can lead to significant anxiety, stress and feelings of loss or grief. Children may feel they have done something wrong if you have less time or emotional energy for them. Helping children understand the impact of caring and providing the opportunity to talk can help them realise it's not their fault.



Things that can help include:

- Give them some time to talk about their feelings. They may be angry and afraid as well as sad, and talking about their emotions can help
- Establish what they understand about dementia. It might be helpful to clarify what it is and how it can affect people. The animation and information above can help
- Look out for local support dementia services such as Admiral Nurses who may be able to offer support to children OR there may be some groups for children who are young carers (see below)

3. What if a child has become a carer for someone with dementia?

A child may be a carer for someone with dementia; this may be a grandparent, yourself or your partner. This can be especially difficult if the person has a young onset dementia, as this usually affects the person's ability to work, and will place significant pressure on the remaining parent or the child themselves, especially if in a single parent family.

The charity, Young Dementia, offers useful information about young onset dementia:
www.youngdementiauk.org

Being a young carer can have a significant impact on a young person's health, social life and self-confidence. Many young carers struggle to juggle their education and caring, which can cause pressure and stress. They may start missing school and can be bullied.

The following organisations provide information about the needs of young carers and information about local groups and support networks:

Carers UK: www.carers.org/about-us/about-young-carers

Young Minds: www.youngminds.org.uk/find-help/looking-after-yourself/young-carers

4. Where can I find information about the different types of dementia?

The Dementia UK website provides information on the various types of dementia and how the conditions can affect the person. It can be helpful to describe dementia as a journey: as the condition progresses, each stage of the journey is different, and can affect individuals in different ways.

People with dementia may need more help with the things we take for granted, such as remembering people and their names; washing and dressing and eating, amongst other things. Dementia UK has leaflets and short videos to explain these changes:

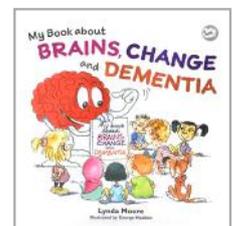
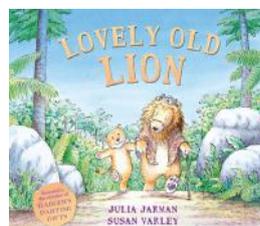
www.dementiauk.org/understanding-dementia/advice-and-information



5. Other resources

For younger children in (5-8 year olds) there are a number of illustrated books available. Some examples are:

- **Lovely old lion** by Julia Jarman
- **When I visit Granny Jean** by Elizabeth Maltman
- **My Book about Brains, Change and Dementia: What is Dementia and What Does it Do?** by Linda Moore



As a follow up to these books, why not suggest creating a memory box, or making picture albums of special events they have experienced.

Fundraising for Dementia UK can be a good way for children to raise awareness about dementia while doing something practical to help other families affected.

Dementia UK has pages on its website of ideas for fundraising for schools:

www.dementiauk.org/support-us/fundraise/support-us-fundraise-school-fundraising-ideas

And an A-Z of activities and ideas for young people:

www.dementiauk.org/support-us/fundraise/a-z-of-fundraising-ideas-for-children

This information was developed as a result of a survey on dementia carried out by Year 7 pupils at Belvedere Academy in Liverpool.