

# Keep Talking ABOUT DEMENTIA



Information for Siblings and Professionals  
about Down's Syndrome and dementia

**Down's Syndrome**  
**SCOTLAND** / helping people realise their potential

# Introduction

It is widely known that the life expectancy of people with Down's syndrome has increased throughout the years to over sixty in many cases.

This longer life expectancy now leads to many people with Down's syndrome outliving their parents. In some families, it means that a sibling often becomes the main carer for their brother or sister with Down's syndrome. This often happens at a time when adults with Down's syndrome are experiencing changes in their health.

Many of these changes are treatable, if detected, such as depression, hypothyroidism or problems with eyesight or hearing. No change should ever be ignored.

Down's Syndrome Scotland can provide information on health conditions that people with Down's syndrome may be more prone to. One significant health change may be the onset of dementia. Symptoms of

this can include a loss of daily living skills, confusion for no obvious reason and a deterioration in communication. These indicators are more common than memory loss, which is apparent among people who do not have Down's syndrome.

The knowledge of dementia and the issues that arise when dementia is diagnosed are likely to be different for siblings and professionals, with one group not always recognising the needs of the other.

Recent research at Down's Syndrome Scotland has considered this issue. This booklet looks at the most relevant issues that were highlighted, for both siblings and professionals. It also emphasises the need for ongoing contact between the two.

Above all, the person with Down's syndrome and dementia, and their needs, must be central to ongoing communication.

# SIBLINGS

## Dementia Checklist

---

- ▶ If any medical terms are used that you are not familiar with when you are given the diagnosis of dementia for your family member, you must ask for clarification.
- ▶ The diagnosis of dementia should be discussed with your brother or sister with Down's syndrome and others who are close to them.
- ▶ You should be given the option of being involved in planning for the future needs of your sibling.
- ▶ It can be beneficial for people with dementia to remain in familiar accommodation for as long as possible, if this is their preference.
- ▶ Talking to professionals earlier about changes in health behaviour or emotions can increase the likelihood of an earlier diagnosis.
- ▶ An earlier diagnosis can lead to medication being prescribed that may be suitable for patients in the early stages of dementia.
- ▶ Communication should be increased and maintained with the professionals or care providers, who work with your family. This communication should be a two way process.
- ▶ It is vital that you are able to express any need for support for yourself, or your relative with Down's syndrome, without feeling that it will be seen as an inability to cope.
- ▶ The use of life story work is recommended. This can include a photo album, video diary or a memory box. This can capture the past for the benefit of the person with Down's syndrome and their future carer.
- ▶ Information about the later stages of dementia should be sought in advance of your family member reaching that stage. Although difficult, it will allow for discussion over their future wishes.

# PROFESSIONALS

---

- ▶ Caring may be new to siblings. Do not assume that they have all the information that they need.
- ▶ Siblings may take on an increased caring role at a time when they have other commitments such as children of their own, or employment. They may also be caring for a parent.
- ▶ The relationship between siblings is likely to be the longest that a person with Down's syndrome will ever have. Siblings will have more background knowledge and information to give than anyone else.
- ▶ Whether or not siblings live near their family member with Down's syndrome, does not necessarily affect the nature of their relationship.
- ▶ Generally, siblings do not plan ahead for the future care of their family member with Down's Syndrome. This does not mean that support and information will not be appreciated when a diagnosis of dementia is made.
- ▶ Conflict may arise between family members if they disagree with one another or if siblings disagree with parent's wishes. This can complicate an already stressful situation.
- ▶ Siblings are reluctant to share their concerns with professionals due to their fear of being thought unable to cope.
- ▶ Where applicable, it is often the oldest daughter who is asked by parents to take over as the main carer for their sibling with Down's syndrome.
- ▶ It is often the sibling who got on better with their brother or sister with Down's syndrome when they were children, who actually takes over the caring role. This is not necessarily the oldest daughter.
- ▶ Negative relationships between siblings as children may determine the nature of their adult relationship.

# Dementia Checklist

- ▶ It must not be assumed that it will be a sister who takes over the main caring role after the death of a parent. Brothers are carers too.
- ▶ Sisters may access information more pro actively by seeking advice. Brothers may be more likely to rely on information being given to them directly, which does not always automatically happen.
- ▶ A willingness to care for their brother or sister with Down's Syndrome and dementia is not an indicator of the sibling's knowledge or understanding of dementia, or of the course of the disease.
- ▶ Siblings are not usually aware of the link between Down's syndrome and dementia.
- ▶ Siblings notice changes in the health of their relative with Down's syndrome in advance of this being detected by professionals, although are often not aware of the implications.
- ▶ Siblings do not communicate these concerns until they are also detected elsewhere.
- ▶ Professionals working in nursing homes, hospitals or hospices have usually not had any training in working with people who have a learning disability. Support and training should be provided.
- ▶ Professionals working with people who have a learning disability do not usually have any training in dementia. Support and training should be provided.
- ▶ The design and environment of homes and buildings should be considered in relation to the care of people with Down's syndrome. This includes living and sleeping arrangements on a lower floor, careful use of decor, mirrors and furnishings plus labelling and a logical use of rooms. Down's Syndrome Scotland can provide more information if required.

# Summary

The knowledge of dementia among siblings of people with Down's syndrome is limited, even after a diagnosis has been made. Siblings knowledge and understanding of dementia is based on what has been learnt retrospectively.

This leads to a lack of awareness of issues that need to be planned ahead for, such as the environment, accommodation, appropriate interventions and medical care.

Siblings often need to seek information for themselves to a greater or lesser extent. Siblings are often reluctant to seek information from, or share it with, professionals.

Professionals hold the information and the knowledge that is vital for siblings to plan ahead with their family member. Two way communication is the key to unlocking the door that will lead to information being shared with siblings and the person with Down's syndrome and dementia. This is essential for future planning.

Much more information is required by both siblings and professionals about all stages of dementia, and especially the end stages, in people with Down's syndrome.

Recognising the role of siblings and increasing the knowledge and awareness of dementia among people with Down's syndrome and their families is vital.

# Further Information

Further information available from Down's Syndrome Scotland.

- ▶ *Let's Talk About Getting Older* by Lou Marsden, 2003.  
A booklet about ageing for adults who have a learning disability.
- ▶ *It's Your Move* by Karen Watchman, 2002.  
Information sheet and advice for GPs and health practitioners when detecting dementia in people with Down's syndrome.
- ▶ *Let's Talk About Death* by Karen Watchman, 2001.  
A booklet about death and funerals for adults who have a learning disability.
- ▶ *Food For Thought* by Karen Watchman, 2001.  
A guide for supporting people with Down's syndrome and dementia at mealtimes.
- ▶ *What Is Dementia?* by Diana Kerr and Mo Innes, 2001.  
A booklet about dementia for adults who have a learning disability.



# Down's Syndrome

**SCOTLAND** helping people realise their potential

158/160 Balgreen Road, Edinburgh EH11 3AU

Tel 0131 313 4225 Fax 0131 313 4285

E-mail [info@dsscotland.org.uk](mailto:info@dsscotland.org.uk)

Internet [www.dsscotland.org.uk](http://www.dsscotland.org.uk)

**Down's Syndrome Scotland provides support, advice and information to people with Down's syndrome and their families, carers, professionals and the general public in Scotland.**

**It also seeks to raise awareness and understanding of the potential of people of all ages with Down's syndrome.**

Written by Karen Watchman

Published by

**Down's Syndrome Scotland**

This edition printed November 2003

Thanks to Aileen and James Fender,  
Grace Johnstone and Alice Grieve

SCOTTISH CHARITY NO. SC011012