Sight Scotland

life changes trust

COMMUNITY FUND

Dementia and Sight Loss

A guide on activities and care for people living with dementia and sight loss based on learning from a Sight Scotland Rights Made Real project funded by the Life Changes Trust.

Tackling vision loss together

About Sight Scotland

Sight Scotland is Scotland's largest visual impairment charity. Formerly known as Royal Blind, the charity was founded in 1793 and is one of the oldest national charities for sight loss in the world.

We provide care and support that empowers people affected by sight loss in Scotland, including learning at the Royal Blind School and education outreach services; residential care for children and young adults with visual impairment and complex needs; and specialist care and support for older people living with sight loss. The Scottish Braille Press provides supported employment for disabled people and is a leading provider of accessible media. Our sister charity, Sight Scotland Veterans, formerly known as Scottish War Blinded, was initially created by Royal Blind, and provides free support to ex-servicemen and women affected by sight loss in Scotland, regardless of the cause, to help them regain confidence, restore their independence and make new connections.

Sight Scotland has been at the forefront of providing care and support for blind and partially sighted older people for over two centuries, both through residential care and rehabilitation for people who have developed sight loss in later life. We are committed to supporting the independence of older people with sight loss, delivering person-centred care for visually impaired older people living with other conditions, and raising awareness of visual impairment in care provision in Scotland.

Sight Scotland Dementia and Sight Loss Project

Our philosophy of care has been developed through working with people we provide care to in order to understand their needs and expectations of us as their caregivers. We believe in providing care which helps people to be independent, to take part in the activities they enjoy and which are important to them. This is key to people living well with dementia and sight loss.

We also recognise the challenges in ensuring people with visual impairment and dementia are involved in activities and receive appropriate care for both conditions. As age is the biggest risk factor for both sight loss and dementia, these needs will increasingly have to be understood and met by care providers supporting an ageing population. Not every care provider will have specialist expertise in sight loss but visual impairment awareness is important to ensure care and activities for blind and partially sighted people are person centred.

We wanted to develop a better understanding of which activities are most fulfilling for people with dementia and visual impairment, and how they can be included in developing activity programmes. This led us to apply to the Life Changes Trust for an award from the Rights Made Real in Care Homes project, and we were delighted to be awarded £20,000 to take forward this work over two years. Rights Made Real in Care Homes is an exciting project, funded by the Life Changes Trust and delivered in partnership with Scottish Care and the University of the West of Scotland. The overall aim is to improve the quality of life of those living in a care home and to help support staff to not only recognise, but embed human rights in their everyday practice. You can find out more about the work of the Life Changes Trust at www.lifechangestrust.org.uk.

The Dementia and Sight Loss Project was launched in April 2019. The aims of the project were to:

1. Improve knowledge and awareness of what activities and support best meets the needs of people with dementia who are also visually impaired.
2. Ensure the wishes and preferences of people with dementia are at the centre of activities organised for them to participate in.
3. Promote learning and awareness of how to provide person-centred care in care homes for people with dementia who also have sight loss.

The project took place in Jenny's Well Care Home in Paisley, a specialist care home for older people with sight loss where 80% of the residents also had a diagnosis of dementia, and was officially launched in April 2019. It had been anticipated a learning event would be held to conclude the project at the end of 2020, but these plans had to be changed as a result of the Coronavirus pandemic. As a result of the need to protect residents and respond to the critical situation all care homes faced at such an extraordinarily difficult time, the project in Jenny's Well was affected.

However, although the later stages of the project were affected, there had already been significant learning which has informed the development of this guide. It has been developed as part of the aim of the project to promote awareness and learning on dementia and sight loss, and we hope it will be found informative and useful.

Contents

Dementia and sight loss

Facts about dementia and sight loss

Age is the biggest risk factor for both dementia and sight loss. Scotland's population is ageing and this means that an increasing number of people will be living with both conditions in the future.

Today, there are around 90,000 people in Scotland living with dementia and 178,000 people who are visually impaired.

95% of people with dementia are over the age of 65. Around one in seven of over 65s are living with significant sight loss. This means there are around 12,500 people in Scotland living with dementia and sight loss today.

By 2030, the number of people in Scotland who have dementia is forecast to increase to around 110,000 and the number of people living with visual impairment to over 210,000. This means that in 2030 there will be around 15,000 people living with dementia and sight loss.

Visual impairment is also a symptom of certain types of dementia, including vascular dementia, dementia with Lewy bodies and posterior cortical atrophy. Symptoms can include problems with depth of perception and spatial awareness and, for some forms of dementia, hallucinations. It is important in providing person-centred care for some people with dementia that it is recognised memory loss is not the only symptom or even the prevalent symptom of the disease for them.

95%

of people with dementia are over the age of 65

Sensory impairment and dementia

Having been diagnosed with Alzheimer's Disease in 2006, Agnes Houston was driven to campaign for greater awareness of the sensory challenges which can be symptoms of dementia, and better information and resources for people with dementia and sensory impairment. Agnes, who is also a member of Sight Scotland Veterans, has led high profile campaigns on dementia awareness, developed a range of resources for people with dementia, and won a Churchill Fellowship award to take forward her research. In 2015 she was awarded an MBE for her work in the field.

Agnes, who wrote 'Talking Sense – Living with Sensory Changes and Dementia' with Dr Julie Christie of the University of Edinburgh, says:

"Think dementia, think sensory, think environment. That's talking sense about dementia and sensory challenges. The lived experience of people with dementia is increasingly informing our understanding of dementia and this is especially true in regard to sensory changes. When I received my diagnosis of dementia, I discovered not only was there little support for continued independence, but what support there was had virtually no awareness of the common experience of sensory change. I wrote 'Talking Sense' to offer much needed knowledge, support and, most of all, hope. Whether senses are changing due to ageing, as a direct result of dementia or a combination of the two, 'Talking Sense' offers the latest information and tips in an easy-to-read format to enable understanding and quality of life."

> **"The lived experience of people with dementia is increasingly informing our understanding of dementia…"**
>
> – Agnes Houston

’Talking Sense’ is available online at:

www.dementiavoices.org.uk/wp-content/uploads/2019/05/Talking-sense.pdf

The book seeks to introduce dementia and sensory challenges as a subject area for those providing care and support for people with dementia, and all those affected by dementia. It offers advice and information on a range of sensory issues so that GPs, nurses, allied health professionals and also care home staff can recognise when people with dementia have a support need related to sensory issues.

‘Talking Sense’ highlights that sight loss can often be under-diagnosed in people with dementia because one condition can mask or be mistaken for another. Vision problems in dementia are sometimes referred to as ‘brain blindness’ where despite the eye appearing to be healthy the person still has visual impairment. In this case, the issue is not with vision but with the person’s perception of what they are seeing. It is crucial that people with dementia actively seek advice on how to improve vision and in care homes are supported to do so. Regular eye checks and the right spectacles may make all the difference. As age is a key risk factor both for dementia and sight loss, it is vital that residents with dementia have regular eye checks. If a visual impairment can be identified and either corrected or the resident given support to cope with sight loss and care which takes it into account, this can make a significant difference to their quality of life.

As well as 'brain blindness' and dementia which can result in visual impairment such as the loss of peripheral vision, visual hallucination can be a symptom of some types of dementia. Visual hallucination can be as simple as seeing flashing lights or as complex as experiencing animals or people in bizarre situations. Some hallucinations do not make the person feel anxious or threatened, whereas other hallucinations can be frightening, and the person may react accordingly. Some people with dementia have reported that they have vivid dreams and when they wake up, the dreams remain a reality. Charles Bonnet Syndrome (CBS) is a type of visual disturbance where people with partial or severe blindness experience visual hallucinations.

CBS hallucinations are only caused by sight loss. You don't need to have dementia to experience these. They are caused by a lack of visual information to the brain and as a result the brain then fills in the gaps with its own images.

Esme's Umbrella is the campaign group for everyone working towards a greater awareness of Charles Bonnet Syndrome: www.charlesbonnetsyndrome.uk

Agnes was also supported by the Life Changes Trust to produce a peer to peer resource 'Dementia and Sensory Challenges': www.lifechangestrust.org.uk/project/dementia-and-sensory-challenges

The Dementia and Sight Loss Project

Design of the project

The project was taken forward at Jenny's Well, a 54-bed purpose-built home for visually impaired people living with other health conditions including dementia and frailty. The care home was opened by Sight Scotland (known then by the charity's former name Royal Blind) in October 2017 and was purpose built to support older people with complex care needs.

In April 2018 the activity hours at Jenny's Well were increased from 60 to 144 hours per week, reflecting a commitment to ensuring that social and emotional needs are viewed as being as important as meeting physical care needs.

The plan for the project was:

Summer 2018

Training for staff and design survey for residents on activities, with input from the DEEP network.

Winter 2018

Commission and organise activities based on the preferences expressed by residents in the surveys and focus groups.

Spring 2019

Consult with residents on which activities they had most enjoyed and review activities based on these responses as well as staff feedback based on residents' reactions at the time of the events.

In May 2018 the charity was awarded funding of £20,000 over two years from the Life Changes Trust Rights Made Real in Care Homes project. The project aimed to promote human rights and encourage a person-centred approach by improving the knowledge and awareness of what activities and support best meets the needs of visually impaired people living with dementia.

The great majority of the project was able to be completed before the Coronavirus pandemic but activity was affected from Spring 2020 when all the focus of staff at Jenny's Well was on ensuring the safety of residents and dealing with the exceptional challenges resulting from Covid-19.

Summer 2019

Using findings from evaluation process of previous activities and further consultation with residents, design a new programme of activities to run through until early 2020.

Spring 2020

Develop information resources for care homes, based on learning through the project, on the provision of support for visually impaired people with dementia in care homes to ensure they can continue be active, stimulated emotionally and intellectually and continue to have a good quality of life.

Summer 2020

Publish learning resources and organise an information sharing event to promote the findings of the project.

Consultation

Ensuring the wishes and preferences of people living with dementia are at the centre of activities organised for them to participate in was a key element of the project. The first phase of the project was centred on gathering the views of residents to get a baseline of current perception of provision of activities, listen to what residents wanted and plan for the future.

In August 2018 we designed a questionnaire for residents which was a combination of yes/no answers, satisfaction scales and open questions. Staff and families supported the residents to complete the questionnaires by acting as their scribe. An additional pictorial questionnaire was developed for use with residents who had advanced dementia. This used a large print thumbs up and thumbs down visual and these questionnaires were completed over a period of time. The staff member would assess their level of engagement and ability to participate. If the resident was struggling or was becoming overwhelmed the staff member would leave and return at a later time.

We also held two focus groups at Jenny's Well to allow for broader discussion around participation in activities. For the focus groups we used the same questions as were contained in the questionnaire. Ten residents took part in the focus groups, 12 completed questionnaires, and four completed pictorial questionnaires.

Project findings

Questionnaire responses

For residents who filled in the questionnaire, on a scale of 1 to 5 with 1 being Very Unhappy and 5 being Very Happy, 83% of residents gave scores of 3 to 5 in response to the question on whether they were happy with the level of activity offered. The same response (83% scoring 3 to 5) was received to the question on whether they were happy with the availability of activity. However, two thirds of residents then said there wasn't enough to do in the home and almost 60% said that there weren't enough different things to do. This suggests residents did want a greater range of activities, and as the home was in the process of recruiting additional activities staff at this point this was perhaps not a surprising response. Residents most frequently reported that they took part in activities twice daily (34%) but the most popular frequency for activities was actually once daily (25%). Residents responding to the pictorial questionnaire gave similar responses, except that all those respondents felt there was enough activities, and enough different activities, in the home.

34%

of residents reported that they took part in activities twice daily.

25%

of residents reported that they would prefer to take part in activities once daily.

Focus group discussions

The questionnaires provided valuable learning in themselves and also informed the questions discussed in the two focus groups held in Jenny's Well. Although some distinct issues were raised in each focus group there were many similarities in the points made by residents in the two groups.

Wanting to be asked their view

Residents wanted a clear structure for activities and to be asked their view about what they wanted to do each day. Points raised included that the day's activities should be outlined at the start of each day; residents should be asked more what they want to do; most residents wanted there to be activities once a day, in the afternoon; and there should be more help for residents to establish new friendships.

Being more active

Residents wanted to get out more and be more active. This included residents saying they would like more trips outside the home; assistance to go for short walks; a set day to go out for a short walk and a coffee and cake; helping staff out with simple duties like laundry; learning to cope with sight loss and being as independent as they can.

Preferred activities
Residents gave us their view on their preferred activities, and most frequently said they wanted to take part in included listening to music; watching dancing; story reading; dominoes; theatre; outings; bowling; quizzes and singing. Some residents, but not all, also enjoyed listening to talking books.

Personal development
Residents also talked about activities linked to personal development and their wish to continue to learn new things. Along with learning skills to cope with sight loss, residents enjoyed historical talks and expressed enthusiasm for studying new languages. Many residents who had been part of faith communities before moving into the home also wanted more opportunities to participate in worship.

Taking the activities forward

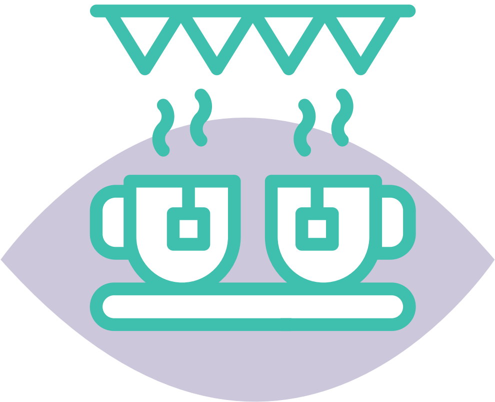
We organised activities to respond to the preferences and activities highlighted by residents through the surveys and the focus groups:

Being involved

Outlining the day's activities at the start of each day
We added boards around the home to allow residents and family members to know what is happening each day. We also used images to help residents with their visual impairment to see the larger image easier. These boards were changed first thing on a Monday morning for the week.

Resident planning group and asking residents more what they want to do
We developed a resident planning group, however we found that the residents felt most confident to suggest their ideas in a smaller group (max three) or on a one-to-one level.

Activities once a day in the afternoon
Prior to the restrictions resulting from the pandemic, activities were organised at least once a day and predominantly in the afternoon. However, in taking forward the activities we found that some residents did wish to be involved in activities in the morning, for example newspaper groups.



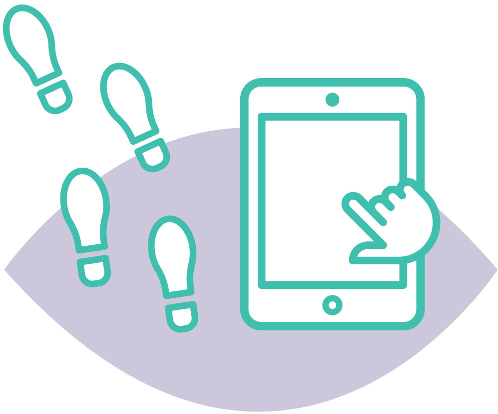
Helping new residents to develop friendships
We ran tea parties with a few residents we felt who could develop into friendships. Although this activity could not be sustained after restrictions were introduced as a result of Covid, it was successful up to this point.

Getting out more/ being active

More trips outside the home. Residents were taken to football matches locally at St Mirren F.C. and for a Christmas lunch with a dance afterwards. A number of residents were assisted to attend the 2019 Remembrance Day ceremonies in Paisley. Families were also encouraged where possible to help with this and take loved ones out. Residents who wished to attend chapel were assisted to do so, and other visits outside the home included one to a local garden centre.

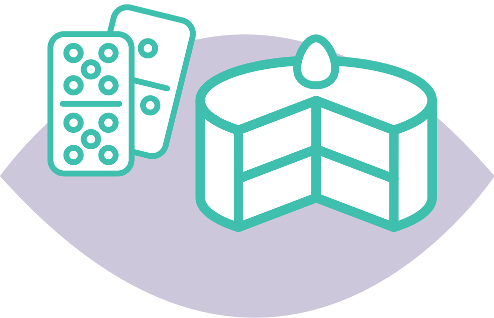
Assistance to go for short walks. We put in place a walking group for residents and loved ones for when they wanted to go as a group. We also put in more effort to engage and encourage residents to go for a walk outside, even just for very short walks. This was very successful.

Helping staff out with simple duties like laundry. Some residents wanted to feel that they were helping out and take part in tasks they had been accustomed to before moving into the home. A number of residents were assisted to help with tasks such as washing dishes, dusting, and folding towels.



Learning to cope with being blind and being as independent as we can. We placed footprints around the main cloister area to help residents maintain their independence and allow them to do as many ’laps‘ within the home as possible, with plenty of opportunity for breaks situated around the cloister. We also supported residents to use assistive technology, such as Amazon Alexa voice-control devices, ’Echo Show‘ and iPads, as well as apps such as ’Bloom‘ which are beneficial from a sensory and emotional perspective. This became increasingly important at those points of the pandemic when we were unable to receive visitors into the home and contact with family members had to be maintained online.

Types of activity



A range of activities in line with residents' preferences. We organised activities which reflected the preferences residents gave in the surveys and focus groups. We organised dancing sessions, quizzes, dominoes, indoor bowling activities and singing sessions. Residents were assisted to take part in gardening and horticultural activities, flower arranging, craftwork (such as carpentry) and culinary activities (such as cake decorating, bread making, soup making). We ensured talking books were provided for those residents who enjoyed them.

Culture and personal development

Historical talks, cultural events and learning new skills and languages. Monthly historical talks were organised in the home and group learning experiences such learning Italian together. Church representatives were invited in the home for those residents who wished to participate in worship. A visit to a theatre followed by a fish tea was organised for residents.

Challenges and learning in consultation

The pictorial survey was developed because it became clear that the survey in its original form was not accessible for residents with more advanced dementia. Although only four residents completed the pictorial survey, with staff asking the questions, this was a much more successful way of learning the views of these residents.

The focus groups worked successfully with small groups of residents, but when we sought to include residents in a larger focus group, of ten residents, this was not successful. A few residents spoke often but some did not contribute at all, despite efforts being made to include them. In the smaller groups of five it was far easier to ensure everyone had the chance to contribute.

The nature of nursing care home provision today is that residents in the home will normally have multiple and serious health conditions, and while in the past residents may have been in care homes for several years before they passed away, this is far less often the case in care homes today. This means it is essential residents are regularly asked what activities they wish to participate in to ensure that the activities meet the needs of the current residents in the home. All the residents in Jenny's Well had sight loss and the great majority had dementia, but of course there was a wide range of preferences for activities which programmes need to accommodate so everyone can be included.

Challenges and learning from the activity programmes

We found that as we had to be flexible in our approach to consulting with residents, this was also true in organising activities as well. For example, the 'newspaper groups' we ran in mornings could develop organically so that the time was spent doing different things which were all led by residents, like a debate group, singing or reminiscence. This would depend on who was in the group or what was in the newspaper that particular day.

Some activities did not work as well as others. Activities which were not so successful are those activities which did not match or reflect people's interests, hobbies and earlier life experiences and/or careers.

As we anticipated when we set out on the project, the activities that worked particularly well for residents living with dementia and sight loss related to those that utilise other senses – touch, hearing, taste and smell – along with those which stimulate positive emotional experiences (such as talking therapy, reminiscence therapy, companionship from befrienders) and a sense of value and self-worth. One of the often overlooked therapies which people have drawn a lot of emotional benefit from relates to something as simple as being supported to go outside for a walk and a chat with a member of staff or a volunteer (on a one-to-one basis with staff or volunteer support – referred to as a "walkie talkie").

As part of capturing the learning from the Rights Made Real in Care Homes project, the Life Changes Trust commissioned the writing of a collection of stories from the care homes showcasing good practice, particularly in relation to observing and promoting people's human rights. It shows that adopting a human rights-based approach is not something people working in care homes should view with anxiety, but instead recognise that it is about building on many of the attitudes they currently possess and activities they currently practise. The summary report and a copy of the Jenny's Well's Story can be found on the Life Changes Trust website: www.lifechangestrust.org.uk/rights-made-real-care-homes-evidence-and-learning.


Lorraine

Providing care and activities for visually impaired people with dementia

Organising activities

It can be challenging for staff to think of ways to ensure that older people who are visually impaired are involved in activities in care environments. Often they find it difficult to be involved in some of the usual activities and do not participate, leading to loneliness and isolation. It is important to know that everything is possible; you just have to change things up a bit.

- **Be descriptive:** If you have someone who is vision impaired, be more descriptive and make best use of his or her other senses.
- **Adapt:** Often a resident can manage what they were doing before with some additional help, for example they can still paint but may use a magnifier.
- **Use sound:** For example when bowling, use a ball with a bell inside or bang a stick to indicate the direction you want the resident to aim for.
- **Alternative formats:** Many board games come in large print versions or are tactile.

Remember:

“I can use my voice to control an iPad or Alexa.”

“There are plenty of board games I can still play – it’s not all dominoes and bingo!”

“Get to know my line of vision and place them accordingly when in a group.”

“Large groups can be overwhelming for me.”

Dementia and sight loss-friendly environments

Many well-established approaches to creating dementia-friendly environments are also beneficial for visually impaired people. Increasing lighting levels and ensuring plenty of daylight in rooms is helpful for people with some, but limited vision. Strong colour contrasts for walls and flooring and handrails, as well as avoiding patterned flooring and cluttered environments, supports wayfinding and mobility.

Several studies have found that fear of falling led to older people with sight loss restricting their mobility. There is often a risk-averse approach from families and staff and they can discourage people from mobilising independently.

- **Wayfinding:** Work with the person to identify their most frequent routes – toilet, dining room, sitting room. Pick a route to practise and gradually reduce the support as their confidence increases. Often people will mentally map their route, e.g. “If I take 14 steps I will be at my door and then I turn left to get to the dining room.”
- **Keep areas clear and clutter free:** Ensure nothing is out of place. If they have a cluttered environment and it is familiar to them, do not feel you have to declutter it.
- **Create a tactile identifier for their room:** Use a cuddly toy, a colour contrast, or their name in bright bold letters. Something they can reach out and touch. This will help build the resident’s confidence in finding their own way.
- **Using wheelchairs:** There is no reason why a person cannot independently use a wheelchair, as most people will have some residual vision. The same rules apply as with mobilising.
- **Offer a ‘commentary’:** When a resident is mobilising (walking or being pushed in a chair) talk them through the process. This allows the resident to know their environment and any hazards approaching, and can ease fears of falling.

Remember:

“Give me the space to be independent.”

“When I can hear your voice, it makes me feel less anxious.”

“Hearing a familiar voice reassures me that you are close.”

Caring for people with sight loss

Communication

Communication is key to everything we do. Ensuring that we are clear in our explanations and taking the appropriate time to communicate can help reduce the loneliness, isolation and anxiety that people who are sight impaired can experience.

- **Explain, describe and reassure:** Always remember that a vision impaired person can find it scary if you approach them without talking to them. Explain each bit of care as you go, especially if you are using a hoist.
- **Speak clearly and slowly:** Use detail and explain what you are doing; be verbally vocal.
- **Introduce yourself:** Wait to make sure they are aware you are there. Sometimes you can use a code/particular knock/sing a song on the door so they can identify you. Assess the person's vision and approach from their 'good' side.

Remember:

"Tell me when you leave me."

"Introduce me to whomever I am sitting beside so I can talk to that person or even know that there is someone else there."

"Staff should explain who they are every time they speak to me."

"Ask me if I can manage that – do not presume I cannot."

"Tell me where things are and guide my hands to the objects in front of me."

Eating and drinking

These tips can make the difference between someone requiring physical support to eat and drink to managing on their own, giving them control over their menu choices and how they eat.

- **Colour contrast:** Think bright and bold. If you use white plates, put a coloured mat underneath. If the food is mainly white, use a dark plate.
- **Avoid shiny things:** They can cause glare and reduce any remaining vision.
- **Use square tables:** Defined edges make things easier to feel.
- **Keep everything in its place:** Guide the resident's hands to the object to help them identify them.
- **Get to know residents' preferences:** For example, Mary likes her apple juice on the top left-hand side.
- **Use a 'clock' system:** Place food in relation to numbers on a clock face. Turn the plate if needed and always think about the resident's vision impairment.
- **Reassure:** Residents may feel embarrassed when it comes to 'missing their mouth'. Reassure them and make sure they have a napkin.
- **Explain:** Speak about the food choices and cut up food if asked.

Remember:

"Explain what is on my plate and the area around it."

"Make sure I know where my food and drink is before you leave."

"Communicate with me and ensure I have a calm dining experience."

"Clear my used things out of the way."

Maintaining independence

It is important that everyone is supported to be independent to ensure that they maintain control of their life and live the life they wish. Having a vision impairment often means everyday tasks take longer and it is sometimes easier and quicker for well-meaning staff to overhelp. Taking a little bit of extra time can make a huge difference for older people with sight loss.

- **Offer choices:** From which colour to wear; trousers or skirt; what jewellery; colour of nail polish – many residents will know exactly what is in their wardrobe and can tell you what they want to wear.
- **Describe the outfit:** Let them feel the clothes to help them choose.
- **Keep their possessions in the same place:** Don't move it without telling them.
- **Encourage independence:** Get them to do their own care, even if it takes longer. Guide and supervise. Don't do it for them.
- **Use a person-centred approach:** Think about what the individual might like and enjoy doing. Observe how the resident orientates him or herself to their environment helps the carer understand their needs, habits and ways in their routine.
- **Use colour contrast:** Use dark towels, dark plates under light food, put medication on a contrasting colour – small things can change dependence to independence.
- **Aids:** Consider what aids and technology might help.

Remember:

> **"Staff always ask me to do things before they try to help me."**

> **"Make sure everything is within reach and use my hand to touch items so I know where to reach."**

> **"I have been able to see for most of my life. I may not see colours anymore but I can mostly remember."**

> **"Time is required and often prompting."**

Aids and equipment

Non-slip colourful mats

Adjustable lamps

Hand-held magnifier

Talking clock

Useful contacts and publications

Sight Scotland is the leading organisation for sight loss in Scotland. You can find out more about our work and a range of information resources on visual impairment at **sightscotland.org.uk**.

You can contact us via email at **hello@sightscotland.org.uk** or phone us on **0131 229 1456**.

You can find out more about the work of the Life Changes Trust at: **lifechangestrust.org.uk**.

Sight Scotland (under the charity's previous name Royal Blind) also produced a publication on care of older people with sight loss called Hints and Tips for Carers **sightscotland.org.uk/articles/information-and-advice/hints-and-tips-caring-older-people-sight-loss**.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