

Learning Resource 1.1: My Portfolio

Use this to record the changes you would like to make in your work practice to support people with learning disabilities to have a good life as they grow older.

<p>Module 1</p> <p>Reflection on your practice: Write down one thing you have learnt about the experience of people with learning disabilities as they grow older. Also, write down one change you will make in your practice as a result of thinking about this.</p>	
<p>Module 2</p> <p>Hopes and wishes: what will be your first step to find out about the hopes and wishes of someone you support?</p>	
<p>Module 3</p> <p>Getting the right healthcare in later life: what idea will you take back to your work to improve people's access to the right healthcare as they get older?</p>	

<p>Module 4</p> <p>Being connected to others: What idea will you try out in the next few weeks to maintain or build the connections of someone you support?</p>	
<p>Module 5</p> <p>Comfort and safety at home:</p> <p>What idea will you follow up with a person/ people you support to talk about changes they would like to make to their home for it to feel safer or more comfortable? What will be your first step?</p>	
<p>Module 6</p> <p>Looking after yourself:</p> <p>Write down two ideas about the support you would find helpful in relation to bereavement and dying, for example, personal development, training, mentoring or on the job support.</p>	

Learning Resource 2.1: Hopes and wishes

	How you might do this?
What communication tools will you use to ask about their hopes and wishes (e.g. what words and phrases, photos, pictures, objects)?	
What would be a good setting to ask someone (e.g. on their own, with others to share ideas, in a place where they feel relaxed/can reflect)?	
Who else might you involve (family, friends, others who know them well)?	
How will you record what they tell you and make a plan to achieve it (e.g. pictures, voices, photographs)?	
What will you do first?	

Learning Resource 3.1: Common health changes, conditions and diseases to be aware of

	Changes to look for
Sensory	<p>Common eye problems include cataracts, glaucoma and macular degeneration. Changes to vision including difficulty seeing in low light.</p> <p>Difficulty hearing higher pitched voices and sounds and hearing in busy places.</p> <p>Accumulation of earwax.</p> <p>Changes in taste and smell.</p>
Digestive system	<p>Digestion of food more difficult.</p> <p>Swallowing and digestive reflexes slow down.</p> <p>Swallowing may become more difficult. Problems with reflux.</p> <p>Constipation.</p>
Kidneys and urinary tract	<p>Kidneys become less efficient. Diabetes and high blood pressure can cause damage to kidneys. Greater risk of kidney failure among people with learning disabilities.</p> <p>Urinary incontinence can be a symptom of hormone levels in women and enlarged prostate in men.</p>
Weight	<p>Lower levels of physical activity and a slowing metabolism may contribute to weight gain. Some drugs, including anti-psychotic drugs, can lead to weight gain and a higher risk of developing Type 2 diabetes.</p> <p>Weight loss may occur as result of swallowing difficulties or a loss of appetite. May be an indication of an underlying illness such as cancer.</p> <p>Greater risk of obesity among people with learning disabilities.</p>
Diabetes	<p>There is a higher rate of both Type 1 and Type 2 diabetes for people with learning disabilities compared with the general population.</p> <p>People with Down's syndrome have a higher risk of Type 1. Complications can arise, such as amputations.</p> <p>Diagnosis, management and consistent support are all important. Find out about reasonable adjustments, for example, in relation to structured education programmes and access to commercial weight management programmes in your local area.</p>
Posture and movement	<p>Bones shrink in size and density and are more prone to fractures and osteoporosis.</p> <p>Muscles, tendons and joints may lose strength and flexibility.</p> <p>Poorer balance leading to an increased risk of falls.</p>

<p>Hair, skin and nails</p>	<p>Skin becomes drier and more brittle.</p> <p>Lower level of sweating results in greater susceptibility to heat stroke and heat exhaustion.</p> <p>Hair and nails grow slower and become brittle needing a higher level of attention.</p>
<p>Heart, lungs and circulatory system</p>	<p>High blood pressure (hypertension) – swollen ankles can be a symptom. Atherosclerosis (hardening of arteries).</p> <p>Greater risk of heart disease, hypertension, stroke and respiratory diseases (such as pneumonia).</p> <p>Aspiration pneumonia as a result of matter from the stomach or mouth getting into the lungs.</p>
<p>Brain and nervous system</p>	<p>Brain cells decrease leading to memory loss. Can also lead to reflexes slowing down, co-ordination difficulties and being more easily distracted.</p> <p>There is a greater risk of dementia among people with learning disabilities.</p> <p>People with learning disabilities and epilepsy are more likely to have other health problems, such as arthritis, gastrointestinal disease, at risk of stroke and also have a higher rate of fractures.</p>
<p>Mental health and well-being</p>	<p>Changes in sleep patterns. Sleep problems can be an indication of poor health or chronic health problems.</p> <p>Increase in anxiety and depression.</p>
<p>Sepsis</p>	<p>Although sepsis is rare it is important to have an awareness of it as the signs are often missed yet the infection needs to be treated urgently. It can quickly lead to severe sepsis or septic shock which, in turn, can cause organ failure and death. The person may not have a fever or high temperature but just feel very unwell. People with learning disabilities may have a number of pre-conditions that put them at greater risk.</p>
<p>Thyroid disease</p>	<p>The incidence of thyroid problems increases with age but is sometimes difficult to diagnose as there may be a reduced number of symptoms or they may not be as obvious as those in younger patients. Hypothyroidism (under-active thyroid) is the most common thyroid condition in people over 60 years of age: symptoms, such as confusion, memory loss, depression, falling, heart failure and constipation are frequently missed as they are also signs of common illnesses of older people.</p>

Resources and references

Look on the internet for Easy Read information on specific health problems often produced by specialist health organisations or charities. In addition, the website EasyHealth (www.easyhealth.org.uk/) has Easy Read health leaflets, videos and advice.

There are many Books Beyond Words publications about health including Going into Hospital, Getting on with Type 2 Diabetes, Looking after my Heart, Looking after my Eyes. For more information, see: <https://booksbeyondwords.co.uk/bookshop/>

Learning Resource 3.2: Kamal's story

Kamal is 62 years old and lives in a house with two friends. There is always support at the house in the day time and a support worker sleeps in at night. Kamal gets anxious and is on medication for low level depression. Over the last few years staff have noticed that Kamal was doing less around the flat, generally not very confident when walking around and was becoming withdrawn. He went for an eye test and was diagnosed with a cataract which gradually got worse and now requires surgery. Kamal is very anxious about going to hospital and having the operation but he understands he needs to do something as his sight is getting worse and he has said he will have the operation. Kamal needs time to process information and he finds pictorial information helpful as he can look at it over time.

What can staff do to help Kamal:

- Before he has his operation?
- At the hospital on the day of his operation?
- Aftercare when he is back home?

Before the operation	1. 2. 3.
At the hospital	1. 2. 3.
Aftercare	1. 2. 3.

Learning Resource 3.3: Ideas to support Kamal

<p>Before the operation</p>	<ul style="list-style-type: none"> ■ Hospital passport with a one-page summary of information relevant to health staff for cataract operation. ■ One-page Profile of Kamal – ask if he would like it to be shared with hospital staff – both medical and reception staff. ■ Find out what he wants to know about the day of the operation e.g. would he like to visit the hospital beforehand, does he want to know the details of the operation. ■ Create a story board of what will happen on day. ■ Think about whether Kamal has any cultural or religious needs in relation to his hospital visit. ■ Use literature from relevant organisations, such as RNIB, to understand what will happen on the day and aftercare, and use this to give Kamal the information he wants or so staff know and can be prepared. ■ Look for Easy Read information (when you search ‘people with learning disabilities and cataract operations’ you find SeeAbility has produced Easy Read information about cataract operations. They also have created an Eye Surgery Support Plan). ■ Plan support hours so that support staff who know him well and help him cope with his anxiety, are supporting him the day before, on the day and the next day. Let him know who will be with him. ■ Find out his past experiences of hospital appointments and treatments and find out what worked/didn’t work. ■ Ask him and others who know him well what might help him to relax e.g something to listen to or hold. ■ Think about what reasonable adjustments, under the Equality Act, may be needed. An example of this could be asking the Consultant or booking clerk if Kamal can have the first operation of the day (if that would help with his anxiety). ■ Find out if the hospital has a Learning Disability Liaison Nurse. ■ Ask Kamal if he has any questions he would like to ask the consultant when he has a pre-op assessment. Write them down in Easy Read so he can take them with him. ■ Discuss at the pre-op appointment whether additional sedation is an option and explain this to Kamal.
<p>At the hospital</p>	<ul style="list-style-type: none"> ■ Make sure he has his hospital passport and one-page profile with him. ■ You could ask to be alerted when Kamal leaves the operating theatre so support staff can be with him in the recovery suite

Aftercare	<ul style="list-style-type: none">■ Plan the aftercare beforehand with Kamal – ask if he would like this written down in a way he understands and can think about.■ Explain that after surgery he will need to be still for the length of time the Consultant has said. Find out what he would like to do in that time – is there an activity he would enjoy that would be distracting?■ Explain to Kamal before the operation about eyedrops and eye patch which will be part of his aftercare – ask Kamal if he would like to practice wearing the eyepatch beforehand and try out eyedrops using Artificial Tears.■ Plan additional support if Kamal needs 1-1 support afterwards to be still.■ Be observant during Kamal's period of recovery and if there are any causes for concern or changes in Kamal's well-being, seek medical advice as he may not be able to indicate pain, be aware of infection or any other problems.
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Useful resources

EasyHealth website: www.easyhealth.org.uk

Books Beyond Words publication *Going into Hospital*

Learning Resource 4.1: How to keep people connected with others

	Reasons people may lose connections as they get older?	Suggestions to maintain existing connections or build new connections?
Family	<ul style="list-style-type: none"> ■ Parents may have died or be very elderly themselves, they may have mobility difficulties or health problems making it difficult to travel or to have their son or daughter to stay. ■ Other family members, such as siblings, cousins, nieces and nephews, may not be sure how to be involved in a person's life and be supportive. 	<ul style="list-style-type: none"> ■ Look for alternative ways to be in touch with elderly relatives such as using on-line video (e.g. Skype), phone calls, support to send cards and presents. ■ If parents have died, find out how the person would like to keep their memories alive, for example having a memory box, acknowledging anniversaries ■ Give support to build contact with other family members such as siblings, cousins, nieces and nephews. Give support to collect and share contact details. ■ Find out from the person you support how they would like family members to be involved in their life and share ideas with family members. Some ideas to look at: would they like to be included in family events, do a shared interest together, reminisce together about family life, act as an advocate at reviews or when decisions need to be made.
Friends	<ul style="list-style-type: none"> ■ Friends may be ageing themselves and finding it difficult to go out or meet up. ■ Younger friends may be getting impatient with the person becoming slower and less keen to spend time together. ■ Friends may have moved away or died. ■ Shared interests with friends may have changed as they have both got older. 	<ul style="list-style-type: none"> ■ Talk to the person about their friends or find out by using a relationship map (see link in resources at end of the chapter) with people who know them well. ■ Support the person to create a phone book with friends' names and contact details and make sure this is kept up-to-date. Use the book to talk with the person about their friends and what they might like to do together – give support to arrange this. Find out who shares an interest. ■ Give support to invite friends over and to visit friends – help to get this pattern established before either finds travelling difficult. If transport such as a taxi is needed, ask for this to be put into a care and support plan. ■ Support someone to organise an activity at their house e.g. a friend or group of friends come to do a craft activity, watch football, have a pizza.

	Reasons people may lose connections as they get older?	Suggestions to maintain existing connections or build new connections?
Work/ volunteering	<ul style="list-style-type: none"> ■ Reached retirement age. ■ Retired because job has become too difficult. ■ Stopped volunteering because it became too tiring. ■ Finding the journey difficult. 	<ul style="list-style-type: none"> ■ Use work skills to find a volunteering role, become involved in a community project or do something for a friend or neighbour. ■ Look for more manageable job or voluntary work/negotiate less hours. ■ Arrange to keep in touch with ex-work mates, sharing contact details and keeping in touch with anyone who was a friend at work. ■ Look for a valued role somewhere else, such as becoming a trustee of a local charity, joining an advocacy group, becoming a quality checker in a health or social care service.
People and places in the community	<ul style="list-style-type: none"> ■ Difficulties traveling to places. ■ Activities become tiring. ■ Changing interests with age. ■ Need to leave a centre or service because of age criteria. ■ Centres or services not making reasonable adjustments or being inclusive of people as they get older. ■ Other people in community places lack the patience to slow down and give the person the time they need. 	<ul style="list-style-type: none"> ■ Look for activities in the community for older people, either specific for people with learning disabilities or open to everyone e.g. healthy walks, lunch clubs, singing groups, classes. ■ Depending on person's ability, they (or with the help of their support worker,) can help a community activity to become more inclusive of people with a learning disability. ■ Give support to the person to say hello, chat or become involved with other people at the activity so that they don't just go along but become connected with others there.

Learning Resource 4.2: Your ideas to support someone you know to keep connected with others

	What has / might become difficult as they get older?	What could you do to maintain existing connections or build new ones?
Family		
Friends		
Work/ volunteering		
People and places in the community		

Learning Resource 4.3: Joyce's story

On a Friday, Joyce goes to a community centre in her local town for a line dancing class followed by a meal at the lunch club. She lives in a village and has a 40-minute bus ride to get there travelling with a support worker. Jenny has got slower walking from the bus stop to the community centre and so it is a bit of a rush to get to the class in time for the start. When she arrives, she is often stressed and rushes to the toilet. Sometimes she says she wants to stop coming. But she is much more cheerful when she hears the music and starts to join in the dance movements. She sometimes says 'My legs are getting tired'.

Until a year ago Joyce helped to lay the tables for lunch in the half hour between her class finishing and lunch being served but now she's no longer encouraged to do this by the lunch club as she isn't able to get it done in the time available. She usually sits on her own waiting for lunch. At lunchtime she seems to enjoy chatting to the people sitting next to her. But on the way home she seems to be tired and anxious and when the support worker asks her what's wrong she says she thinks she might stop going to the centre as 'it's all too much'. The support worker isn't sure what to do as she knows Joyce is at home the day before and the day after, and that much of the time she seems to enjoy being at the centre.

How do you think she should talk to Joyce about this and what suggestions might they explore together?

Learning Resource 5.1: Making changes at home: ideas

What difficulties is someone facing?	Ideas to consider
Feeling cold around the house	<ul style="list-style-type: none"> ■ Warmer bedding ■ Having extra rugs beside the bed or on chairs ■ Thicker curtains ■ Heating on a slightly higher setting ■ Cosy clothing such as thermal t-shirts and socks, fleece and sleepwear ■ Warm coloured soft furnishings and pictures on walls
Aches and pains when sitting in a chair or lying in bed	<ul style="list-style-type: none"> ■ Having a good quality chair and mattress with the right level of support. ■ Having cushions and pillows for support. ■ Having foot/ leg support ■ Having a riser-recliner chair to help get in and out ■ Having chairs with arms to give support whilst sitting and to use to stand up ■ Where necessary, getting advice from specialists, such as occupational therapists, about seating and beds
Eyesight getting poorer making it more difficult to see objects, read numbers on cooker and instructions such as recipes etc.	<ul style="list-style-type: none"> ■ Regular eye tests ■ Extra lighting, lamps close by where needed ■ Maximising natural light by keeping windows clean, pulling back curtains and not placing furniture in front of windows ■ Use of contrasting colours, uncluttered surfaces ■ Larger print information ■ Large faced clock ■ Photos of people on phone rather than names ■ Stickers
Hearing getting worse making it more difficult to hear conversation, the doorbell, phone, TV or radio	<ul style="list-style-type: none"> ■ Regular hearing tests ■ Reducing background noise ■ Having headphones to listen to music ■ Wireless flashing doorbell
Finding it more difficult to go to meet friends and family	<ul style="list-style-type: none"> ■ Receiving support to invite people to their house and making it a positive experience ■ Creating a pleasant space for visitors to sit, have a cup of tea or a meal, do activities together ■ Using on-line video call, such as Skype

What difficulties is someone facing?	Ideas to consider
Helping to reduce trips and falls	<ul style="list-style-type: none"> ■ Storage space to remove clutter from the floor ■ Keeping top and bottom of stairs clear ■ Enough sockets so electric leads not over the floor ■ Grab rails to hold onto when moving around such as by the toilet, on stairs and steps / fitting a second bannister ■ Easy read fall prevention advice ■ Call alert – can be to another room in the property or to a call centre ■ Occupational Therapy assessment
Finding it harder to grip things, open containers, pick things up from the floor, take food out of the oven or microwave, stand whilst cooking etc	<ul style="list-style-type: none"> ■ Adaptations such as lever taps, easy grip kitchen utensils ■ Easy-reach grabbers to pick things up ■ Kettle tipper ■ Perching stool to have support in a near-standing position
Finding it hard to remember things such as where to find things, when to take medication or to have regular drinks.	<ul style="list-style-type: none"> ■ Assistive technology such as a call alert, reminder to take medication ■ Hooks in obvious places to hang keys, coats or bags ■ Ask people about how they would like to store things, such as clothes and food, so fits with any changes to ways they do things ■ Store things in clear containers ■ Encourage people to keep things in same place and reduce clutter ■ Have a whiteboard or magnetic board
Finding it hard to relax	<ul style="list-style-type: none"> ■ Supporting people to access relaxing music or relaxation tapes ■ Look at <i>Talking Together: Facilitating peer support activities to help people with learning disabilities understand about growing older and living with dementia</i> which has two activities to help people relax, Activity 16: Relaxation and Activity 17: Music and relaxation (www.togethermatters.org.uk)
Carrying shopping	<ul style="list-style-type: none"> ■ Look at on-line shopping and home delivery
All areas	<ul style="list-style-type: none"> ■ Considering whether an Occupational Therapy, Speech and Language Therapy or Physiotherapy assessment could be helpful and make a referral ■ Use resources and information for people who are getting older, living with a disability and/ or dementia, such as the Disabled Living Foundation dlf.org.uk, Age Uk and Alzheimer's Society (see links at end of chapter)

Learning Resource 5.2: Making changes at home: template

What difficulties is someone facing?	Ideas to consider
Feeling cold around the house	
Aches and pains when sitting in a chair or lying in bed	
Eyesight getting poorer making it more difficult, for example, to see objects, read numbers on cooker and instructions such as recipes	
Hearing getting worse making it more difficult to hear the phone, radio or TV or conversations	
Finding it more difficult to go out and wanting to invite family and friends to visit them	
More shaky walking around and at risk of trips and falls	
Harder to grip things, open containers, pick things up from the floor	
Harder to remember things such as where to find things, when to take medication or to have regular drinks	
Other	

Learning resource 6.1: Reasons for including people

Reasons for including people	What do you think?
It is their right to know that something is happening that affects them, and to express their emotions and receive or give support.	
They should not be denied the opportunity to learn coping skills: skills are learnt step by step and it is easier if these can begin to be developed with a person they are not too close to. May help to be slightly more prepared when someone close to them is ill or dies or they are faced with their own serious or terminal illness.	
Being silent gives the wrong message about expressing emotions, implying that they should be bottled up, which in turn can lead to mental ill health and changes in behaviour.	
Avoiding difficult subjects can make people unsafe if they think their feelings don't count: people need to know they can talk about difficult things and will be supported (e.g. feeling down, being abused).	
People often have a smaller network of people in their life and are often in a dependent relationship. Therefore, individual relationships are likely to have a greater significance.	
They may be losing an important role in their life such as being a son, daughter, partner or best friend. They may also have been a carer for the person so would additionally be losing that role.	
It is likely to be more frightening and distressing not to know what's going on: the person who is ill may be changing physically and emotionally, which could be scarier to see if it is not known that the person is ill.	
Other – add other reasons that you think are important.	

Learning Resource 6.2: Lloyd's story

Lloyd is 56 and his close friend Ben has died. Ben lived at home with his family and Lloyd lives in a house he shares with two other people. Lloyd had support to visit Ben at the hospital and hospice so saw the changes in his friend but support workers are unsure how much Lloyd understands when he was told Ben had died. A support worker has asked Lloyd if he would like to go Ben's funeral and he has indicated he doesn't want to go. However the worker wasn't sure if Lloyd understood what a funeral is or had enough information to make a choice as to why he might go or not go, but isn't sure what to do next. Lloyd has never been to a funeral and when his older sister died his family didn't want him to go to her funeral as they thought it would upset him. Lloyd uses a few spoken words and can answer simple questions but often likes things explained with images and objects as well as words.

Think about what you could suggest to the support worker. You might want to think about one of these aspects:

- Finding out Lloyd's understanding of 'dying' and of funerals.
- Explaining to Lloyd what happens at a funeral and why people sometimes choose to go or not to go.
- Giving Lloyd some other options to say goodbye to his friend instead of going, or as well as going, to Ben's funeral.

Pens and paper are available if you want to draw some ideas as well as write down ideas.