Making a difference together: Key messages

Short, accessible summary points for
healthcare professionals when supporting
people with a learning disability

- Understanding learning disability
- Reasonable adjustments
- Access to health care
- Safe health care
- End of life care
- Understanding loss and bereavement
- Understanding dementia
- Understanding autism
- Resources for appropriate support
- References

○ Understanding learning disability

Hospitals can be scary and largely unfamiliar places. They have lots of different people, all speaking in a language threaded with technical terms and complicated jargon. The people who work there all wear different uniforms, of different designs, in different colours. Hospital buildings are usually spacious, but many corridors and wards all look the same. Unless you work in a hospital they can be quite daunting.

Imagine if you couldn't read, had never been to a hospital before, were on your own and feeling unwell, and struggle to talk with strangers. A taxi has just dropped you off outside, but you didn't know what Accident and Emergency means, and don't know who to approach and ask. This is what visiting a hospital might seem like to someone with a learning disability.

The Department of Health (DH) define having a learning disability as '*…the presence of a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood, with a lasting effect on development' (DH, 2001)*. Having a learning disability can mean so many different things to different people. It may mean that a person struggles with abstract concepts; some people might need variable care and support to help them to do the everyday things that people ordinarily enjoy in life.

Understanding learning disability

Some may struggle with conventional communication. However, some people with a learning disability may cope independently, and have husbands, wives and families of their own.

Making a difference together

DVD

Films:
Understanding autism
Going into hospital
Making a difference together
Conversations about death and what it means

Powerpoints:
Understanding autism
Understanding access to healthcare
Understanding dementia
Understanding loss and bereavement

DVD **Understanding autism**
listening to young people,
families and professionals

Remember:

- A learning disability is not the same as a learning difficulty
- Having a learning disability may not mean that a person has different health needs, it means that the person may need reasonable adjustments to have their health needs best met
- Think about how people with a learning disability might help you to understand how to care for them better
- Never assume that the person cannot understand because of their learning disability
- Not everyone will have a diagnosis of having a learning disability, they will simply present as needing a little more time and understanding
- Most people with a learning disability live at home with their family
- Communication is very important, and sometimes words and phrases need to be repeated or spoken in a different way
- Use your skills, knowledge and experience when listening to people
- Keep the person with a learning disability involved in all aspects of their care
- Communication using images and technology can help people
- Don’t give too much information too quickly, break it down
- Ask for training about living with a learning disability for you and your colleagues
- The films in the toolkit will help you to understand more about learning disabilities

Reasonable adjustments

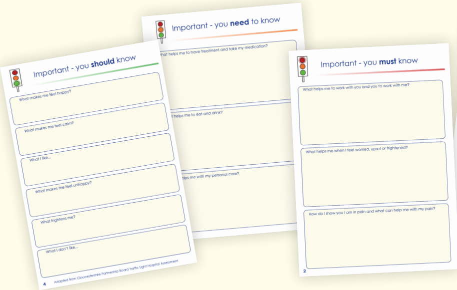
It would be much easier for healthcare professionals if everyone was the same; could easily and quickly adapt to unfamiliar environments; could understand complex words and technical terminology; and could follow instructions. But everyone is unique and different, and some people need a little more support and time to understand and digest new information and to find their way around new places.

Making 'reasonable adjustments' (Michael, 2008) in any healthcare environment means taking fundamental steps to help someone to understand what is happening around them or to make them feel more comfortable in an unfamiliar setting. Reasonable adjustments can help anyone who struggles with communication, has sensory impairments, has a learning disability, or just needs a little more time and consideration from healthcare professionals.

Making reasonable adjustments to the way you work can involve making small practical changes to an environment; being more flexible (for example) around appointment times; providing additional information in an accessible, clear format.

Remember:

- Don’t try and treat everyone the same as people are all different
- Think of ways to involve people with a learning disability in all aspects of their care
- Use clear words and images to support communication
- Think about how the environment can help the person to feel more at ease and comfortable
- Consider what you might do to prepare for people who might need reasonable adjustments where you work
- Consider how you can help the person with a learning disability to understand their health needs
- Ask for training about making reasonable adjustments where you work
- Use the Hospital communication passport (in the Toolkit) to find out as much as you can about the person



Important - you **should** know

What makes me feel happy?

What makes me feel calm?

What I like...

What makes me feel unhappy?

What frightens me?

What I don’t like...

4 Adapted from Gloucestershire Partnership Board Traffic Light Hospital Assessment

Important - you **need** to know

hat helps me to have treatment and take my medication?

t helps me to eat and drink?

lps me with my personal care?

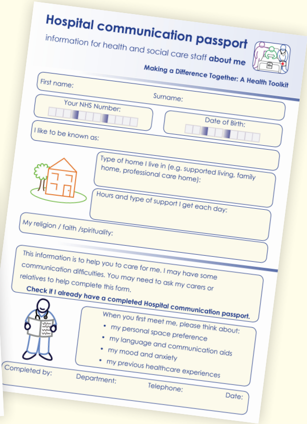
Important - you **must** know

What helps me to work with you and you to work with me?

What helps me when I feel worried, upset or frightened?

How do I show you I am in pain and what can help me with my pain?

2



Hospital communication passport

information for health and social care staff **about me**

Making a Difference Together: A Health Toolkit

First name:

Surname:

Your NHS Number:

Date of Birth:

I like to be known as:

Type of home I live in (e.g. supported living, family home, professional care home):

Hours and type of support I get each day:

My religion / faith /spirituality:

This information is to help you to care for me. I may have some communication difficulties. You may need to ask my carers or relatives to help complete this form.

Check if I already have a completed Hospital communication passport.

When you first meet me, please think about:
- my personal space preference
- my language and communication aids
- my mood and anxiety
- my previous healthcare experiences

Completed by:

Department:

Telephone:

Date:

Access to healthcare

Historically, campaign reports have highlighted that when a person with a learning disability needs to access the health care system, they are likely to receive different care and treatment than the average person who does not have a learning disability (Mencap 2004; Mencap 2007; DH, 2009; Mencap, 2013). Michael (2008) recognised that a lack of awareness of the health needs of people with a learning disability, particularly in primary care, was important. This is the single point of access to health promotion and ill health prevention in addition to health care and treatment.

Michael (2008) made 10 key recommendations for healthcare practice, underpinned by the key themes of leadership, quality and political priority. Fundamentally, Michael (2008) argued that all the necessary policies and procedures already exist to protect vulnerable adults in health services; what is required is for professionals to make reasonable adjustments to these environments to ensure equal access and treatment for all.

This Toolkit has been designed to support access to healthcare particularly for people with a learning disability, but it will also be useful to other vulnerable groups.

○ Remember:

- Become familiar with all the resources available to you
- Recognise those people who need a little more support and time
- Try to understand what it is like to live and die with a learning disability
- Consider how new information/ systems/ treatments can be accessible for people with a learning disability
- Check how accessible your work area is, and how accessible it is to people who cannot read
- Listen to carers and other people who know the patient well
- Explore how comfortable and accessible waiting areas are for people using wheel chairs or those with sensory impairments
- Ask for training about health and learning disability for you and your colleagues
- Use the ABCD Checklist (in the Toolkit) to see how well your environment measures up

They didn't tell me I would need
ney were closed over Christmas wher

Access to the service:

Please ☑ tick the 'yes' or 'no' box

Does the patient have clear information about their appointment and what they need to do? Yes ☐ No ☐

Does the patient have clear directions to the building? Yes ☐ No ☐

easy to get into the building? Yes ☐ No ☐

ance clearly marked? Yes ☐ No ☐

to the building? Yes ☐ No ☐

and shut? Yes ☐ No ☐

to use with a Yes ☐ No ☐

itable for a Yes ☐ No ☐

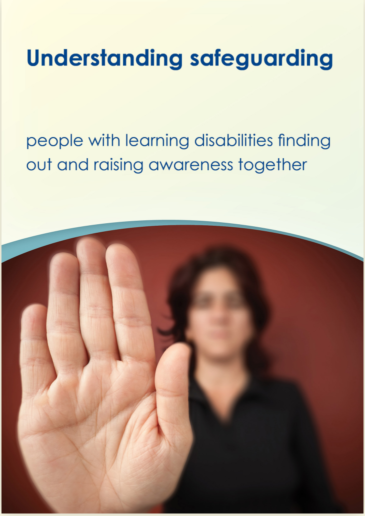
to? Yes ☐ No ☐

Safe health care

This Toolkit can be used to support all patients who can be described as vulnerable, and this includes patients whose first language in not English. You have a duty of care to all of your patients, colleagues, your employer, yourself and the general public.

It remains everyone's responsibility to recognise and support a person who is vulnerable whilst receiving healthcare. Therefore professionals need to ensure that they are aware of any local inter-agency, vulnerable adult's policy and procedures within their local Trusts.

It is also important that all professionals attend regular training updates around vulnerable adults when this is available within their own localities.



Understanding safeguarding

people with learning disabilities finding out and raising awareness together

○ Remember:

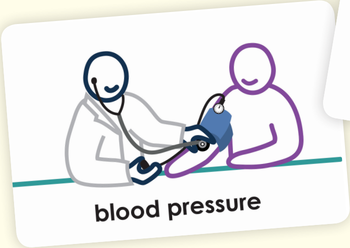
- The 6 Safeguarding principles underpin safe working practice (see Safeguarding Vulnerable Adults book on a ring in this Toolkit)
- Think about how you might recognise a potential vulnerable adult
- Be fully conversant with categories of abuse within the safeguarding context
- Use safeguarding information in different formats to support people who cannot read or those whose first language is not English
- Identify who the safeguarding champion is in your work area
- Never make assumptions about anyone's capacity to consent based on age, appearance or medical condition
- Think about how to involve people with a learning disability in best interest discussions i.g. enlisting advocacy support
- Never ask carers to sign consent forms for anyone over the age of 18
- Treating people with dignity and respect is paramount at all times
- The Assessing Capacity Chart (see Safeguarding Vulnerable Adults book on a ring in this Toolkit) is a useful tool
- Explore the booklet 'Understanding safeguarding' in clear words and pictures, developed with people with a learning disability

End of life care

Everyone will come to a dying part in their lives, whether it is a sudden death, or a protracted one borne out over months or years. People with a learning disability have the same palliative care needs as the general population but may have additional or specific needs relating to specific impairments or the social consequences of impairment (Ryan et al, 2014). As people with a learning disability are living longer, they are experiencing the range of malignant and non-malignant conditions that accompany such longevity.

Supporting people with a learning disability at the end of life might prove difficult for generic healthcare professionals because of reciprocal communication challenges; attitudes, expectations and negative assumptions around learning disability; lack of knowledge about learning disability and its impact; difficulties in recognising ill health; difficulties in accurate assessment, diagnosis and treatment; and capacity and consent issues. It's important to think that if the person did not have learning disability, would they be treated any differently than if they had a learning disability. If the answer is 'yes' then this needs to be constructively explored.

Death can occur at any age, and the resources around end of life care and bereavement in this Toolkit may be useful to healthcare professionals across the lifespan, since they address issues around explaining hospice care to children and young people; spirituality; and questions that people might want to ask. The communication pictograms and app also include prompts around serious ill health, treatment and bereavement and funerals.



Remember:

- Holistic support at the end of life is fundamental to the potential for a peaceful or easeful death
- Use your skills, knowledge and experience when listening to people
- When communicating with people with a learning disability conversations should be in clear language and short sentences
- Think about ways of helping a person with a learning disability to understand the severity of their illness
- When breaking bad news, always try to include a familiar carer, be guided by the person with a learning disability, and answer questions openly and honestly
- Consider how you can help the person with a learning disability to understand their health needs
- Think of ways to involve people with a learning disability in all aspects of their care
- Ask for training about end of life care for people with a learning disability for you and your colleagues
- The Disability Distress Assessment Tool (DisDAT) may prove useful to support practice (Regnard, 2007)
- Pain assessment tools should be used carefully with people with communication difficulties, to ensure that all expressions of distress are not automatically treated with analgesics (Ryan et al, 2014)

○ Understanding loss and bereavement

Loss can be described as a sense of being deprived or being without, and as such can be expected or unexpected. Death is usually perceived as the hardest, greatest loss to accommodate, perhaps because of its finality, permanence and irreversibility. Bereavement can be defined as the state of loss caused by death (Attig, 2011), whilst grief has been described as a response to loss or prompted by change and readjustment (Parkes, 1996). Mourning has been described as the process of accommodating the loss (Worden, 2009).

Some people with a learning disability struggle with conventional communication, and may be excluded from difficult conversations around loss, dying and death (Read, 2014). People with a learning disability are frequently deliberately excluded from death and dying processes (Read & Elliott, 2003). Family, friends and well-meaning health care professionals often seek to protect people with a learning disability from the stark reality of sadness and loss; as if by protecting them and not talking about it, loss simply won't happen, or the person with a learning disability will not express reactions to loss (Read, 2014).

People with a learning disability do experience loss and bereavement, but may express their response to loss differently than expected.

Remember:

- Loss always occurs in a social context, which is crucial in facilitating grief support (i.e. the hospital may be the starting point for this grief work)
- Avoid using euphemisms when explaining about loss and death, they can be misleading and confusing
- Find out what the person knows already about what is happening and build on this
- People with a learning disability may need more concrete information (booklets, leaflets) to support speech (there are several in this Toolkit
- Use clear language and be prepared to repeat it or say it in a different way
- Use your skills, knowledge and experience when listening to people
- People with a learning disability have an external locust of control, and are reliant on so many for so much (Read, 2014)
- People with a learning disability often don't get to do what they really need to do following a bereavement, and sometimes don't even know what they can do
- Knowledge, information and support are important to any person who is experiencing bereavement
- Ask for training about bereavement support for people with a learning disability for you and your colleagues
- Make time and space for supportive conversations with people and their families during times of loss and bereavement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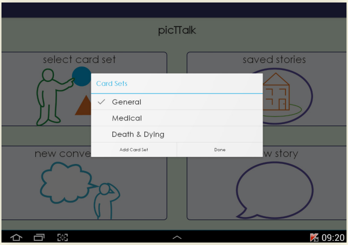
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Understanding dementia

Dementia is an umbrella term used to describe a group of symptoms involving a wide range of diseases and disorders of the brain. This results in progressively deteriorating intellectual functioning, including a decline in cognitive performance and memory. Common types of dementia include Alzheimer's disease, vascular (multi-infarct) dementia, and frontal lobe dementia. Different types of dementia affect a person in different ways.

Since people with learning disabilities are living longer they have an increased chance of developing dementia. Dementia may present at a younger age in people with learning disabilities compared to the general population. People with Down syndrome have a significantly increased risk of developing dementia which is usually, but not exclusively, Alzheimer's disease. The clinical symptoms of this may be present from age 50 years onwards.

Understanding dementia:

A guide for professionals

Making a difference together: A health toolkit

What is dementia?

Dementia is an umbrella term used to describe a group of symptoms. It involves a wide range of diseases and disorders of the brain, with differing causes.

This results in progressively deteriorating intellectual functioning, including a decline in cognitive performance and memory. Dementia is a terminal condition as currently there is no cure.

Common types of dementia include Alzheimer's disease, vascular (multi-infarct) dementia, and frontal lobe dementia. Different types of dementia affect a person in different ways.

People with learning disabilities and dementia

Since people with learning disabilities are living longer they have an increased

ng disability and dementia: Early symptoms

al that dementia is recognised and diagnosed at an early stage. This
s noticing early changes in the person, some of the most common are:

- Short-term memory loss and not recognising forgetfulness
- Apathy, inactivity and a loss of interest in hobbies
- Deterioration / loss of daily living skills
- Reduced communication
- Disorientation and confusion
- Social withdrawal
- Changes in depth perception e.g. difficulties with steps or kerbs
- An increase in wandering for no reason

out other possibilities

shouldn't assume that all changes in a person's
status are dementia related. A number of
ions may mimic symptoms of dementia and
to be ruled out, for example:

pression: similar symptoms
uding withdrawal; less
ive; sleep problems; loss of
rest; and confusion

- Medication side effects
- Dehydration
- Poor diet and/or malnutrition
- Bereavement

○ **Remember:**

- Dementia may present atypically in people with Down syndrome, where changes may initially manifest as behavioural rather than cognitive
- Diagnosing dementia is more difficult when someone has a learning disability
- Noticing early changes in the person is crucial to aid the diagnostic process
- Use your skills, knowledge and experience when listening to people
- It is vital that dementia is recognised and diagnosed at an early stage, so that appropriate treatment can begin
- Work together with families and carers to find out more about the patient
- Ask for training about dementia care for people with a learning disability for you and your colleagues
- To help a person with a learning disability to understand dementia use the booklet ‘Understanding dementia’ in the Toolkit

Understanding autism

Autism is a spectrum condition that affects how a person communicates with, and relates to, other people, and how people make sense of the world around them. There is no cure for autism and the cause remains unknown.

The core idea is that the brain functions differently so people receive and process information in a different way (Forrester-Jones, 2014). The support required by each person with autism can vary from constantly to occasional support. Autism not only affects the person but can also affect the lives of their family, friends and carers. The film in this Toolkit (Understanding autism) was developed to illustrate the lived experiences and impact of autism, impact of autism on individuals and families and the professional experiences of those supporting them. The accompanying booklet explains autism in clear words and pictures, incorporating short vignettes to illustrate ways of practical support in a meaningful and accessible way.

Understanding autism:
A guide for professionals
Making a difference together: A health toolkit

What we understand by the term autism

Autism is a spectrum condition that affects how a person communicates with, and relates to, other people, and how people make sense of the world around them. There is no cure for autism and the cause remains unknown.

The core idea is that the brain functions differently so people receive and process information in a different way (Forrester-Jones, 2014). Autism manifests in different ways, but everyone is unique with abilities, talents, and symptoms.

In this guide, the term 'Autism' is used to include: Autistic Spectrum Disorder, Autistic Spectrum Condition, Asperger's Syndrome, Autistic Spectrum Difference and Neuro-diversity.

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Understanding autism
people with learning disabilities finding out and raising awareness together

○ Remember:

- Not everyone who has autism has a learning disability; and not everyone who has a learning disability has autism
- Recognise that people with autism can have other health needs too
- Understand that some people with autism can find it difficult to comprehend verbal and non-verbal communication
- Use your skills, knowledge and experience when listening to people
- Support people with autism to express how they (and others) might be feeling
- Be aware that people with autism may struggle with their day to day lives
- Help people with autism to adjust to change in the best way for them
- Remember that people with autism have their own personalities, likes and dislikes
- Consider the needs of people with autism who may struggle in noisy environments, and often communicate better one-to-one
- When using nonverbal communication, remember that people with autism may feel uncomfortable with eye contact
- Ask for training about autism for you and your colleagues
- To help a person with a learning disability to understand autism use the booklet ‘Understanding autism’ in the Toolkit

Resources for appropriate support

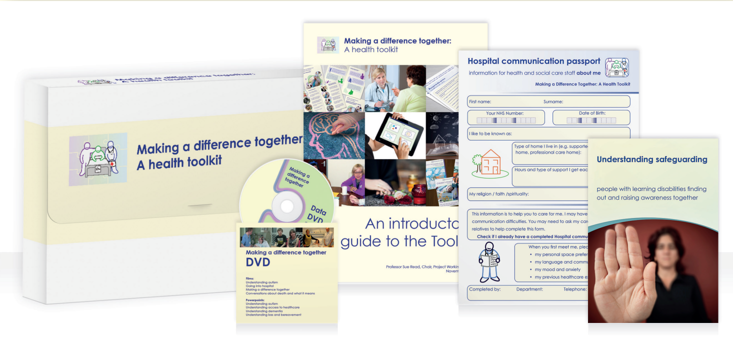
Resources are designed to support healthcare professional to care for patients. There are a number of resources available for a whole host of different patient groups, health conditions, and health settings.

The Toolkit has over 40 resources across three specific themes (Access to healthcare; Safe healthcare; End of life care), some of which are produced in different formats. For example, pictogram communication cards are available in small credit card sized format; as larger flashcards on a ring; and are freely available as an app on iPad and android devices. Such flexible formats allow for usage at the hospital bedside and in community settings. The resources also support healthcare for people with a learning disability across their lifespan, with information booklets for children and young people and adults in a variety of hospital and community settings (e.g. hospices).

Communication is an underlying thread that runs throughout all of these resources. It was never envisaged that a health care professional would sit and read the Toolkit, but to familiarise themselves with its contents so they know what might help them and in what context. Hence they can dip in and out of the resources when they need to access them for a specific purpose.

Remember:

- There is no single prescription for supporting people who are ill, therefore a Toolkit can help a healthcare professional to tailor their support to the unique needs of each patient
- A resource is only as good as the person using it and the context in which it is being used
- Explore the Toolkit and become familiar with its content to help formulate individual support strategies
- Consider how the Toolkit complements existing resources
- Consider how you might use the Toolkit as part of training about learning disabilities for you and your colleagues
- Although designed for people with a learning disability, think about how the resources in this Toolkit may be helpful to others who struggle with communication and cognition



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> **“People with a learning disability are a part of us rather than being apart from us”**
>
> (Todd, 2006, p. 23)

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Acknowledgments:
Reach, Happy Day Design Ltd.