

# 7 STEPS TO EQUAL HEALTHCARE



Providing equal healthcare for people  
who have a learning disability



Working with

**MACMILLAN**  
CANCER SUPPORT

The 7 Steps to Equal Healthcare and supporting information have been created by the Macmillan ENABLE Partnership written by David Campbell with support from People First and Building Bridges (Greater Glasgow and Clyde Learning Disability and Palliative Care Pathway).

These guidelines include extractions from the Considerations for Care document available at <http://www.ldpcproject.co.uk/> written by Allison O'Donnell and Liz Smith.

Design by paulcurrah.com

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# Introduction

The Macmillan ENABLE Partnership was set up to raise awareness on the issues that people who have a learning disability and a cancer diagnosis face and to provide guidance to healthcare professionals on these issues. The partnership developed the 7 Steps to Equal Healthcare set out in this document, which are fundamental building blocks to providing equity and excellence in treatment and care for people who have a learning disability.

The 7 steps are profoundly person centred and put the patient at the heart of any treatment or care given.

All steps are supported through the Your Story Our Guide study and underpinned by the PANEL Human Rights approach.

[http://www.scottishhumanrights.com/media/1409/shrc\\_hrba\\_leaflet.pdf](http://www.scottishhumanrights.com/media/1409/shrc_hrba_leaflet.pdf)

<https://www.enable.org.uk/macmillan-enable-partnership/>

Your Story Our Guide was a study carried out by ENABLE Scotland and Macmillan Cancer Support in 2015/16. It looked at the experience of people who have a learning disability and cancer and sought the views of healthcare professionals and volunteers in cancer services. Some of the main themes highlighted in the study were:

- Attitudes and values
- Patient and treatment/care information
- Communication
- Environment
- Treatment
- Co-production

The 7 Steps to Equal Healthcare also fit in with national guidelines for both learning disability and cancer throughout the UK.

To fulfil the 7 Steps some reasonable adjustments may have to be made by healthcare staff and providers. The UK Government published guidance on this which states:

“Under the Equality Act 2010 public sector organisations have to make changes in their approach or provision to ensure that services are accessible to disabled people as well as everybody else. Reasonable adjustments can mean alterations to buildings by providing lifts, wide doors, ramps and tactile signage, but may also mean changes to policies, procedures and staff training to ensure that services work equally well for people with learning disabilities.

For example, people with learning disabilities may require:

- clear, simple and possibly repeated explanations of what’s happening and of treatments
- help with appointments
- help with managing issues of consent in line with the Mental Capacity Act.

Public sector organisations shouldn't simply wait and respond to difficulties as they emerge: the duty on them is 'anticipatory', meaning they have to think out what's likely to be needed in advance.

All organisations that provide NHS or adult social care must follow the accessible information standard by law. The standard aims to make sure that people who have a disability, impairment or sensory loss are provided with information that they can easily read or understand with support so they can communicate effectively with health and social care services."

The above guidance has been taken from:

<https://www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities/reasonable-adjustments-a-legal-duty>

where further guidance can be found.

The Welsh Government state in Section 3 of the Cancer Delivery Plan for Wales 2016-2020 under the heading Meeting the needs of people affected by cancer.

"Individualised care is the aim for all treatment and care service providers; particularly where the benefits and harms of treatment are closely balanced. This is underpinned by a broader commitment to dignity in care throughout all services."

A major driver of the 7 steps is about ensuring individualised care and support is given.

Beating Cancer: Ambition and Action is the Scottish Government's cancer strategy which was published in March of 2016. The document states the following ambitions:

- People with cancer and their families feeling involved in decision making and able to make the right decisions for them on the basis of full information.
- A radical improvement in experience and quality of life, including at the end of life.
- More equitable access to services and treatment.
- A reduction in cancer inequalities.

These are four of the 7 national outcomes that the Macmillan/ENABLE partnership can contribute towards, detailed in the following 7 Steps to Equal Healthcare.

The principals behind the 7 Steps are also closely aligned to the Scottish Government's strategy for learning disability, The Keys to Life. This document states that:

"The key issue for all effective health care for people with profound and multiple learning disabilities is good communication between the family, carers and all involved health professionals. The importance of listening to the families and carers and respecting their knowledge and experience must be acknowledged by all health staff."

The document also states that:

“There is a need for specialised training for all health professionals on communication and learning disabilities.”

The Keys to life looks at some existing services and states that:

“The outcomes of these initiatives will be the development of an approach in Scotland that guarantees equity of healthcare treatment for all people with profound and multiple learning disabilities – regardless of the extent and complexity of their needs.”

7 Steps to Equal Healthcare was designed to complement this outcome.



# Overview

1. Imagine being me
2. Find out who and what matters to me
3. Listen to me
4. Give me the information that I need, in the way that I need it
5. Think about the space we are in
6. Work with others who are in my life
7. Giving treatment seems too difficult? Think again



HEALTH  
NHS  
Lorna Maxwell  
Adult Oncology Specialist Nurse

NHS  
Lanarkshire  
Wishaw General Hospital  
Lorna Maxwell  
MacMillan Oncology A.N.P.

# 7 Steps to equal healthcare

Providing equal healthcare for people who have a learning disability



Remember to contact your learning disability liaison nurse or community learning disability team for support.

# 1. Imagine being me

The first thing that people who have a learning disability and a cancer diagnosis need is an empathic approach from those charged with their treatment and care. Whilst you already approach patients with an empathic mindset, there are certain additional considerations when supporting someone with a learning disability.

## How would I feel and what would I do if...

- I felt completely out of control?
- I did not fully understand what was happening to my body?
- I did not understand what you were doing to my body?
- I had very negative and scary memories of being in a hospital?
- I could not read any of the comforting body language that you are sending out?
- I am still trying to process the conversation someone had with me an hour ago and you are giving me more information?
- I was very scared?
- I was confused and overwhelmed?
- My senses were heightened to a level that made every day things painful and overwhelming?
- People didn't understand how I communicate or didn't take time to understand?
- I couldn't fully understand why my day to day life and routine have completely changed?

These are all feelings, emotions and situations that a person who has a learning disability may experience when receiving treatment and care from a health professional. Understanding these thoughts and emotions can lead to a better understanding of why someone may react in a more challenging way.



## 2. Find out who and what matters to me

There are specific pieces of information about each individual that can help you care for that person in a truly person centered way. You as a practitioner can be equipped with information that will help you engage with the individual and adapt your practice to fit with their needs, consequently helping the patient feel more able to receive their treatment and care. Some questions to consider about the individual are:

- How do they communicate?
- How do they interact with others?
- How do they interact with the environment around them?
- Is there something in their story about hospitals or medical treatment that might affect how they react around medical professionals or clinical environments?
- What is their medical background, is comorbidity a contributing factor to the way in which their care and support are delivered?
- What are their phobias?
- What helps them stay calm?
- Who are the important people in their life socially?
- How do you get in touch with them?
- Who are the important medical people in their life?
- How do you get in touch with them?
- Should they know about what is happening or be asked to provide any information?

The list above is not exhaustive but provides an example of the kind of information that is essential to the delivery of robust, well delivered treatment and care.

Some people may have documents such as hospital passports, My Health App, Getting to Know Me or a digital passport which can be useful to find out more.

The Macmillan ENABLE Partnership have developed “Things that are important to me”. This document will be filled in by the individual and will help you identify what matters to them. We encourage individuals to keep this document with them and share with staff at each appointment or visit.” Go to [macmillan.org.uk/easyread](https://www.macmillan.org.uk/easyread) to read or order the booklet.

## 3. Listen to me

People with learning disabilities may or may not use words to communicate.

As with any patient, make no assumptions based on appearance or presentation, and be aware that non-verbal communication is still communication.

The tips below have been taken from Considerations for Care, the Building Bridges project guidance booklet available at <http://www.ldpcproject.co.uk/>

### Communication Tips:

- Consider if glasses and hearing aids are fit for purpose and are clean and used as appropriate.
- Consider communication passport and DisDAT (Disability Distress Assessment Tool). Know how to promote good communication ensuring appropriate tools are available when required.
- Consider who accompanies to health appointments. Is it someone who knows the individual and is up to date with their health?
- Use all your communication tools – signs (such as Makaton and Signalong), symbols, pictures, photos, body language, facial expression, tone of voice, gesture, points of reference, technology, social stories etc.
- Consider how prepared you need to be prior to the appointment and what preparation the individual requires.
- Consider the environment – is it noisy/busy/known to provide anxiety.
- Consider time – don't rush, go at the pace of the individual. Arrange longer appointments at the start or end of the day. Arrange additional staff cover if necessary.

### Support Communication by:

- Ensuring you have the person's attention.
- Approaching slowly from the front so that they have time to see you. Smile when approaching someone and identify yourself. Make sure you have eye contact before you touch someone or they may be startled. Face the person if possible and make sure the lighting is adequate.
- Following their lead.
- Asking open-ended questions.
- Backing up speech by showing as well as telling.
- Using short, simple sentences and speaking slowly and clearly.
- Not using jargon.
- Not using abstract language or metaphors (e.g. 'It's raining cats and dogs').
- Checking that you understand what has been said.
- Using consistent language to promote understanding.
- Checking that the individual has understood what has been said. Summarise the discussion and share the information with the care team to enable support with understanding and memory.
- Giving the individual time to process the information and respond.

- Reminding the person of information given. Sensitively remind them of the subject matter if they lose focus. Be flexible in your approach. It may require more than one try before they understand.
  - Be mindful that good speech does not automatically mean good understanding.
  - Working out when the person is more able to concentrate and understand you. Be aware that medication, environment, emotional state, seizure activity, pain, fatigue and other symptoms may affect communication.
  - Encouraging the person to communicate – remember some patients with dementia and other conditions which affect cognitive impairment may forget words they previously used
  - Don't correct attempts at communicating.
  - Better understand the individual's experiences of illness and death.
- When the person does not have capacity and decisions are being made about what they should be told about their condition, consider:
    1. **What** is the person being told about their diagnosis;
    2. **How** much detail should be given;
    3. **What** communication tools may be required and what language and word sequence will be used? Consistency is essential.
    4. **Who** will be involved? Remember that questions may be asked when least expected and may be directed to people who feel uncomfortable answering them. Remember that paid carers will be affected by bad news and need to be considered within the support framework. They also will have a pivotal role in supporting someone to understand the information they are given so should be included as appropriate. Also remember the needs of friends and peers.
    5. **Where** and when they will be told.
    6. **How** that information is shared with other relevant partners to ensure consistency and accuracy.

### Breaking bad news

- Consider using [www.breakingbadnews.org](http://www.breakingbadnews.org) for support.
- Refer to Speech and Language Therapy if required.
- People have a right to know and a right not to know.
- Bad news is not a one-off event. People with learning disabilities may be given bad news at a health appointment but may only understand it later when they're in a different location.
- Carers need then to be very clear about what information has been given and understand it. Easy read information is available and may help.
- If you are asked a question, make sure you understand and that you know the answer. Be honest and don't make assumptions.



## Remember:

- Don't make assumptions.
  - Good, coordinated communication is essential amongst all involved.
  - Involve the person's family and paid carers as appropriate.
  - Use simple language and pictures if appropriate.
  - Consider previous experiences of illness, loss and death.
  - Expect unusual reactions, including behavioural changes.
  - Allow for feelings of sadness, for the individual as well as for you.
  - Consider who else should know, respecting the individual's wishes and how they should be told, e.g. family, friends, peers, day services, college, work, befriender, church, other professionals
  - Learning disability services and teams will work in partnership with teams to support the understanding of the person's communication and other needs linked to their learning disability, and to work through difficult conversations
- Consider using The Dimensions of Loss (Blackman N. Loss and Learning Disability 2003) Emotional; Social; Physical; Lifestyle; Practical; Spiritual and Identity.

## When the person with a learning disability is a carer or family member

- Some families may not wish a diagnosis or poor prognosis to be shared with their loved one with a learning disability. Whilst respecting autonomy it is important to support these individuals to make an informed choice, highlighting both the benefits and risks of such actions.
- Both palliative care teams and learning disability teams must work collaboratively and in partnership to support all members of the family. Early intervention allows time to establish a trusting therapeutic relationship and support planning in a sensitive timely way.

## 4. Give me the information that I need, in the way that I need it

People with a learning disability have a right to know what is happening with and to their body, including about an illness and about treatment. If their capacity to understand information and make certain decisions is under question, please consult with other professionals such as social worker and learning disability nurse – and those closest to the individual.

When consulting, discuss the detail of what the individual is able to understand and how that information is going to be delivered to them. Each person has a preferred method of receiving important information, so please work with everyone to ensure that they receive this important information about themselves in a way that will make sense to them.

You may have to consider alternative and creative methods of sharing information. For example, easy read information, showing and explaining social stories or drawing a diagram.

It is also useful to think about the following information, you may find this in their “Things that are important to me booklet”, however, other professionals and the people close to the individual should be able to help.

- Capacity.
- Adults with Incapacity act.
- Guardianship.
- Power of Attorney.
- Next of Kin.
- Advocacy.



## 5. Think about where we are

The environment that someone with a learning disability is in can play a crucial role in their ability to process and cope with the situation they are in. For example, if the environment is distressing they may not be able to take information on board, retain information, withstand invasive procedures and or wait for long periods of time. Some things to consider about the environment:

- Light, heat and noise.
- High-arousal environment (too much going on).
- Low-arousal environment (not enough going on).
- There are too many people around.
- Nothing to do.
- Restrictions on freedom and movement.
- Lack of privacy.
- Having to share a room or ward with people they have not chosen to be with.
- Being denied what they think they need or want.

The longer that someone with a learning disability is exposed to an environment that they aren't used to, don't understand or that makes them feel pain or discomfort, the more difficult it will be to provide treatment or care and the higher the chance that the treatment will be delayed, abandoned or so traumatic that it will be even more difficult the next time you try.

Some reasonable adjustments can be made to help adapt the environment as much as practicably possible. This can be the difference between someone receiving treatment or not.

There may also be an opportunity to help a person prepare and adapt for their treatment and care through a prior visit. This could be both to process the physical space but also to meet with the team who will be supporting them. If a visit is not possible some photographs or a short film of the area and team may be helpful.

It may also be useful to arrange for the healthcare team to view the patients "Things that are important to me" booklet prior to any appointments.

## 6. Work with others who are in my life

There may be a lot of different people and organisations involved in the everyday life of someone with a learning disability who are integral to their care and support, including:

- Family members.
- Carers.
- Support organisations.
- Allied health professionals.
- Learning disability nurses.
- Social workers.
- Advocates.
- Faith groups.
- Circle of friends.
- Place of work.

These individuals and organisations may play a vital role in helping to join up medical treatment and care with non medical care and support.

The contact information for these important people should be in the individual's "Things that are important to me" booklet found at [macmillan.org.uk/easyread](http://macmillan.org.uk/easyread).

If not, speak to the individual and anyone accompanying them to find out who should be considered when treatment and care is being planned and provided.



## 7. Giving treatment seems too difficult? Think again

If the nature and presentation of someone's learning disability causes difficulties with administering treatment and care, consider ALL options. There may be an alternative method of administering treatment that suits them better and will enable them to have equity of treatment and care.

In some cases treatment may be too difficult or considered not to be of enough benefit, but people with a learning disability must never be discriminated against because of the difficulties their disability presents. Every option must be considered and explored.

If your hospital has a learning disability liaison nurse please contact them. If not please contact your community learning disability team for support or advice.





Being told 'you have cancer' can affect so much more than your health – it can also affect your family, your job, even your ability to pay the bills. But you're still you. We get that. And, after over 100 years of helping people through cancer, we get what's most important: that you're treated as a person, not just a patient.

It's why we'll take the time to understand you and all that matters to you, so we can help you get the support you need to take care of your health, protect your personal relationships and deal with money and work worries.

We're here to help you find your best way through from the moment of diagnosis, so you're able to live life as fully as you can. **For information, support or just someone to talk to, call 0808 808 00 00 or visit [macmillan.org.uk](https://www.macmillan.org.uk)**

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