

Posture Friends:

An Enabling Care Approach for Adults
with a Learning Disability



STOPFALLS



HCPA StopFalls in partnership with Enlight Physiotherapy

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Aims of this Booklet

- To provide an overview of 'Posture Friends'*, the Upskilling Programme of Education in Posture and Enablement, which has been developed for the Hertfordshire Learning Disabilities Sector by HCPA in partnership with Enlight Physiotherapy
- To begin the culture shift towards a more informed and confident workforce (including families) for people with Learning Disabilities in Hertfordshire
- To provide a reference tool for those involved in delivering care in the Learning Disabilities sector, with regards strategies which may help to help an individual to be more comfortable, independent and empowered, (physically, as well as mentally, emotionally, and socially)
- To continue to positively impact the Healthcare system, through enhanced knowledge and skills specific to the Learning Disabilities sector



* Please refer to HCPA's website for more information on Posture Friends Tier Training

Aims of 'Posture Friends'

- **To improve the health outcomes, mortality rates, experiences, and quality of life of people with a learning disability by empowering care deliverers who work in this sector with knowledge about general principles, which will help them to:**
 - **Understand the effects of postural care on:**
 - ▶ Respiratory function (particularly in the prevention of chest infections, including pneumonia and aspiration pneumonia, and recognition of early signs of deterioration)
 - ▶ Eating and drinking (with regards swallowing difficulties and choking risk)
 - ▶ Functional ability and ability to participate
 - ▶ Pressure areas
 - ▶ Pressure on internal organs
 - ▶ Tone and contractures
 - ▶ Pain and agitation
 - ▶ Emotional and psychological problems (including self-image)
 - ▶ Caregivers' own confidence, job satisfaction and stress levels
 - **Recognise signs of discomfort and distress**
 - **Recognise early signs of acute or chronic deterioration**
 - **Understand the importance of an approach which focusses on prevention**
 - **Implement an Enabling Care Approach and foster a 'questioning' mindset**
 - **Optimise the potential for independence**
 - **Have an awareness the benefits of movement and activity, including standing/walking programmes**
 - **Have an awareness of the roles of different Health Professionals, and how and when to signpost appropriately**

Up until now, training initiatives have tended to be more patient/service user specific. This type of baseline education has not, to date, been delivered to caregivers across the Learning Disabilities workforce!



Introduction:

There is now overwhelming evidence that people with a Learning Disability in England are dying prematurely and that these deaths are potentially avoidable!

In 2019, there were 1.5 million people in the UK with a learning disability. ⁽¹⁾ Public Health England estimates that about 2% of the population of Hertfordshire has a learning disability. This equates to 23,500 people, although only one in five is known to GPs ⁽²⁾. One in five of these 23,500 die early ⁽³⁾.

Additionally, there has been a huge amount of fantastic work in the Learning Disabilities care sector, which has been aimed at improving individuals' quality of life, by delivering high-quality person-centred care and support, treating people with love and respect and valuing lives and contributions ⁽²⁾. It has however, become increasingly apparent more recently, that there is an urgent need for training across whole sector, one which has a new focus, and which embeds practices that enable people to improve physically, as well as mentally, emotionally, and socially.

Development has been completed in collaboration with professional partners across the county including Hertfordshire Partnership Foundation Trust, Hertfordshire Community Trust and Hertfordshire County Council. Development has been completed in collaboration with professional partners across the county including Hertfordshire Partnership Foundation Trust, Hertfordshire Community Trust and Hertfordshire County Council. This project has been funded by HPFT to support Residential and Nursing Homes, Supported Living, Day Opportunities and Family carers across Hertfordshire, to improve their knowledge and skills.



Background:

In 2018, the Learning Disability Mortality Review (LeDeR) ⁽³⁾ found that this early mortality amounted to people dying between 20 and 30 years younger than the general population, and this highlighted a shocking health inequality. The review revealed that the most common cause of death was a respiratory infection, which is more commonly known as a **chest infection**.

This emerging information has sparked the realisation about something that has been known in Therapy settings for a long time, and that is: **poor postural alignment can have severe and life-threatening consequences** ⁽⁴⁾. This is because people who have limited mobility and/or poor postural alignment have more difficulty breathing, and are therefore more at risk of developing a respiratory infection, and this is often a result of poor postural alignment.



It is certainly well known that people with Learning Disability, and in particular those with Profound and Multiple Learning Disabilities (PMLD), often have changes in muscle tone as well as reduced mobility, and may often sit or lie in non-optimal positions, which puts them at risk of body shape distortion.

Additionally, something else that has been known in Therapy settings for a long time has recently come to light, and that is:

Body shape distortion is NOT inevitable.

This means

These premature deaths are also potentially avoidable.

To date, it seems that these connections have not been communicated widely enough outside of the Therapy professions. One possible reason for this is the limited availability Physiotherapy resources in the Social Care sector as a whole, as Physiotherapy is funded primarily by Health, and not by Social Care.

Many caregivers (care staff and families) in the Learning Disabilities sector will therefore be unaware of the consequences of body shape distortion. More importantly, they will be unaware of the role they can play, and of the huge impact they can have on improving postural care, and therefore on saving lives!

Furthermore, with the ever-increasing demands on the Healthcare system, it is vital that we continue to improve the culture throughout Social Care, to one which encompasses a more 'enabling' approach. This means educating anyone involved in the delivery of care, with respect to the main factors that can help **detect and prevent deterioration**. Most importantly, it means embedding an ethos aimed at **optimising an individual's potential to improve (or at least, to remain well), and to participate in their life, physically, mentally, emotionally, and socially**.

Whilst this is a challenge for Adult Care Services as a whole, it is even more of a challenge in the Learning Disabilities sector, due to the wide range of complex physical and/or cognitive needs, with which a person with a learning disability may present. People involved in the delivery of care in this sector therefore require a unique, but extremely varied, set of skills, to optimally care for individuals who use its services.

Consequently, there is now a drive to bring this education to caregivers in the Learning Disabilities sector, and to upskill everyone, through an Enabling Care Approach that focusses on postural care. This will raise the baseline level of knowledge and skills across the sector and will help to improve the health outcomes for these individuals. It will also compliment the input and maximise the effect of the Therapy and Community Teams in an increasingly overstretched system.



Posture Friends Training - The Tiers

- This Resource and Upskilling Programme of Education aims to cover the most common challenges that arise when caring for people with a learning disability. Since there is such a wide range of abilities in this group of people (from someone with a profound and multiple learning disability (PMLD) to a person who is much more physically able), not all sections of this booklet will relate to every person. We do hope however, that at least some of strategies will be helpful for the people you care for.

Managers' Strategy Webinar

(Embedding Posture Friends and Enabling Care for people with a learning disability):

- To understand what Enabling Care is
- To be aware of what we teach staff about Enabling Care
- To be aware of the risks of not having an Enabling Care approach
- To discuss strategies for supporting staff in implementing an Enabling Care Approach
- To discuss the challenges in implementing an Enabling Care Approach
- To have an understanding of the importance of using NEWS2/RESTORE2 to spot signs of acute deterioration
- To discuss different outcome measures that can be used to monitor Enabling Care interventions

Tier 1 Introductory Level *(for all staff):*

'A Posture Friends and Enabling Care Approach in the Learning Disabilities sector'

- To understand what is meant by Posture Friends and Enabling Care in terms of optimising potential for independence in an individual with a learning disability
- To be aware of what we teach staff about Enabling Care
- To be aware of the risks of not having an Enabling Care approach
- To discuss strategies for supporting staff in implementing an Enabling Care Approach
- To discuss the challenges in implementing an Enabling Care Approach
- To have an understanding of the importance of using NEWS2/RESTORE2/DisDat to spot signs of acute deterioration
- To have an understanding of the importance of using DisDat to spot signs of distress
- To discuss different outcome measures that can be used to monitor Posture Friends interventions

Tier 2 Facilitator Level *(for team leaders and senior staff):*

- Module 1 - Posture Friends and Enabling Care (2 hours)
- Module 2 - Communication (2 hours)
- Module 3 - Anatomy & Physiology (2.5 hours)
- Module 4 - Posture & Positioning (2.5 hours)
- Module 5 - Therapeutic Handling (3 hours)
- Module 6 - Respiratory (3 hours)

Family Members' Tier

(An Enabling Care Approach in the Learning Disabilities sector):

- Module 1 - Posture Friends and Enabling Care (2 hours)
- Module 2 - Communication (2 hours)
- Module 3 - Anatomy and Physiology (2.5hours)
- Module 4 - Posture and Positioning (2.5 hours)
- Module 5 - Therapeutic Handling (3 hours)
- Module 6 - Respiratory (3 hours)



Key findings on Posture and Health - Timeline:

- The health inequalities in people with a learning disability
- The impact of posture on health and mortality
- The fact that body distortion can be changed

None of this is NEW news!

1976

Fulford and Brown first recognised the effect of postural alignment on the body suggested that the 'squint' and 'windswept' baby syndromes in children with cerebral palsy are deformities caused by the effect of gravity on an immobile child ⁽⁵⁾.



2001

White Paper Valuing People ⁽⁶⁾ demanded a Confidential Inquiry into the premature deaths of people with learning disabilities.

This stated that: "There is an above average death rate among younger people with a learning disability" and that "evidence of available illness and premature death amongst people with a learning disability is a major cause of concern for the Government".

2004

Mencap's 'Treat me right' report and campaign exposed the inequitable healthcare that people with learning disabilities often received ⁽⁷⁾. The report concluded that, although some of the reasons that people with learning disabilities died young were known, an inquiry into the premature deaths of people with learning disabilities should be conducted. Mencap believed this would identify the causes of death, as well as serving as a driver for improvement in the delivery of health services.

2006

Disability Rights Commission (DRC) conducted a formal investigation into the inequalities in physical health experienced by people with mental health problems and people with learning in primary health care ⁽⁸⁾. It stated that "it is overwhelmingly acknowledged and clear from the evidence" that people with learning disabilities and/or mental health problems experienced considerable inequalities in health, and that it was 'not acceptable' that they died younger than other people, and that they are four times as likely to die of preventable causes than people in the general population. The investigation also considered it 'alarming' that little had been done to implement the recommendations of Mencap's 'Treat me right' report.

2007

'Death by Indifference' (Mencap, 2007) ⁽⁹⁾ described the circumstances surrounding the deaths of six people with learning disabilities whilst they were in the care of the NHS. It highlighted the 'institutional discrimination' by healthcare services towards people with learning disabilities and their families and carers and criticised the 'astonishing lack of response' at Government level to the DRC and previous reports. The report once again called for a formal Inquiry to take place.

2008 and 2010

Two national reports highlighted the gap in services to protect body shape for people with profound and multiple learning disabilities ^(10,11). It was noted that early intervention can prevent the need for surgery, and it was recommended that NHS bodies should provide a service that recognises postural care issues and addresses them effectively.

2010

A peer reviewed publication of the predictable patterns of body shape distortion outlined how the chest and spine respond to gravity over time. It also summarised the advantages of symmetrical supine lying, and the pattern of rotational distortion caused by unsupported lying postures, and stated, "The consequences of a failure to protect body shape are far-reaching and can be life threatening, with reduction of internal capacity of the abdomen and thorax compromising the function of vital organs" ⁽¹²⁾.

2011

The National Skills for Health Postural Care Project recommended: "Quality assured and accredited postural care training should be available locally for families and mandatory for cross agency workers within the children's workforce....". It also stated that "Alterations in critical dimensions of the chest are associated with reduced internal capacity of the abdomen and thorax and contribute to secondary complications such as reflux and digestive problems, dysphagia, aspiration and respiratory infection⁽¹³⁾.

2012

NICE recognised the importance of body shape protection in managing spasticity in children and young people⁽¹⁴⁾. They stated the need for a 24-hour postural care management programme that included an assessment of the postural needs of a child or young person when they are asleep or resting. The guidance also recognised the importance of training and support of family members or carers as part of effective postural care.

2013

The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) established the link between a failure to protect body shape and resultant premature death⁽⁴⁾. One of the recommendations was that:

"CCGs must ensure they are commissioning sufficient and sufficiently expert preventative services for people with learning disabilities regarding their high risk of respiratory illness. This would include expert, proactive postural care support".

2015

The Learning Disability Mortality Review Programme⁽¹⁵⁾, commissioned by NHS England and NHS Improvement, was established to: review the deaths of people with a learning disability in England; to provide a framework for the local implementation into practice of any learning gained from those deaths; and to improve the standard and quality of care for people with a learning disability and to address the persistent health inequalities that this group faces.

2016

A review of the evidence highlighted the urgent need for research to establish best practice in "reserving and re-establishing body shape for people with movement difficulties⁽¹⁶⁾.

2018

Public Health England Learning Disabilities Team ran webinars on 'Promoting good postural care to improve health'⁽¹⁷⁾, which highlighted training and workforce development as one of the key actions required for good practice.



2019

NHS England and NHS Improvement published their response to the University of Bristol's third annual LeDeR report (2018), which they stated provided a welcome update on the 'action from learning' taking place⁽¹⁸⁾. The report also set out ways in which services need to change, and how the work can be shared so it can be implemented locally. Clinical Commissioning Groups (CCGs) now have to publish local LeDeR reports that provide evidence of their progress on completing reviews, and about the service improvements they are making as a result of the learning gathered from these reviews.

2019

The UK Government published the 'Postural care and people with learning disabilities: Guidance'⁽¹⁹⁾, which set out ways in which health and social care professionals and family carers can be helped to learn how to support the postural care needs of people with learning disabilities, who are at risk of body distortion. This guidance highlights the need for greater awareness of postural care needs, and for better knowledge about when and why to refer to a Physiotherapist for a postural care programme. It also stresses the importance of partnership working between professionals and people who provide hands on care.

2019

Skills for Health Core Capabilities Framework for Supporting People with a Learning Disability⁽²⁰⁾ was published. This is an update of the Department of Health 'Learning Disabilities Core Skills Education and Training Framework' 2016. This framework was commissioned by Health Education England and NHS England (Learning Disability Programme). It sets out actions to improve understanding of the needs of people with a learning disability and/or autism, to improve their health and wellbeing and to tackle the causes of morbidity and preventable deaths. It also aims to standardise learning disability education and training and to improve the quality and consistency of education and training provision.

2020

The Posture Positive Project⁽²¹⁾ was set up in partnership with NHS England and NHS improvement to explore the impact that the Covid19 pandemic has had on the provision of and experiences on postural care services in England. It found that the changes brought about by the pandemic highlighted and exacerbated problems that were already present in the provision of services for people with a learning disability. Ultimately it resulted in increases in pain and body distortion.

2021

After approximately two years of discussions with stakeholders, HCPA launches 'Posture Friends'.

March 2021

The new LeDeR Policy states that local areas need to show evidence of service improvements made, such as, making sure that care plans are followed, that postural support is provided, and that annual health check health plans are followed⁽²²⁾.

In progress, due for publication April 2022

NICE Guidance on Adults with complex needs: social work interventions including assessment, care management and support.

What is Enabling Care?

The NICE guidance 2017⁽²³⁾ explains Enablement as:

“Assessment and interventions provided to people in their home (or care home) aiming to help them recover skills and confidence and maximise their independence”

This guidance aims to ensure that these staff have the skills to support people to optimise recovery, take control of their lives and regain as much independence as possible”. However, it specifically refers to Intermediate Care Teams.

There is no other guidance on what is meant by the term Enablement and even less on how to create an Enabling Care Approach culture across any of the care settings.

Principles of Enabling Care

For the purposes of this educational framework, an Enabling Approach is one which, (in order to improve wellbeing and quality of life), maximises an individual's potential to improve through:

- Choice
- Empowerment
- Independence
- Positive Risk Taking

It also encourages caregivers to have a questioning mind, which always considers a person's ability to:

- Improve
- Do more
- Do more easily
- Do better, physically, mentally emotionally and socially

A questioning approach considers all factors that may be contributing to how a person presents at any given point, with a view to learning from experience and knowledge. This then informs future situations, thereby promoting a preventative approach.

For example, questioning whether a person has had adequate fluid intake, when they are diagnosed with a Urinary Tract Infection (UTI), should lead to a preventative approach in the future. Similarly, if a person loses weight, it may be that their swallow function needs reviewing by a Speech and Language Therapist, in addition to a review of their dietary intake by a Dietician.

Additionally, it is important to note that, whilst offering encouragement and taking the time to assist a person with a social activity is clearly enabling, the smallest of interventions can be also be enabling; from reducing pain by repositioning someone who cannot move themselves independently, so that their pelvis is less twisted, to spotting signs of a chest infection as early as possible, thereby preventing an unnecessary hospital admission.

Enabling Care – Background

For many years it has been the culture in all Health and Social Care sectors that tasks should be performed for people who are unwell, or in need of care, as they are unable to do them for themselves. This is likely, at least in part, due to a lack of knowledge about the principle of “use or lose it” and thus a lack of questioning, about whether a person has the potential to ‘improve’. Understandably it has therefore been a common expectation that an individual will deteriorate, or at most remain the same, rather than improve. Some individuals have consequently become more dependent, requiring higher levels of care, as a result of doing less for themselves. After all, ‘care’ was not set up with the outcome of rehabilitation in mind (unless specifically prescribed).

Another factor may be that people who are paid to deliver care are generally expected, by everyone involved, to ‘do for’ the individuals. Thankfully this mindset has begun to change over the past few years, with the introduction of the Mental Capacity Act, 2005⁽²⁴⁾ and the Care Act, 2014⁽²⁵⁾.

There has been a wealth of local and national initiatives taking place across the UK Learning Disability Sector, for many years now:

The Joint Health and Social Care Self-Assessment Framework⁽²⁶⁾ was established in 2007, by NHS England and the National Association of Directors of Adult Social Services, and this aimed to help everybody understand what young people and adults with learning disabilities and their families needed, to be able to live a good life, and to be healthy, safe and well.

More recently, in 2018, NHS England and NHS Improvement response to the University of Bristol’s third annual LeDeR report⁽³⁾, stated that many of the reviews described improvements, such as those that enhance people’s lives with high quality person-centred care and support, where they are treated with love and respect, and where people around them value their life contribution.

In addition, the Core Capabilities Framework for Supporting People with a Learning Disability has given very clear guidelines on training that is deemed necessary⁽²⁰⁾.

Nevertheless, the gap in terms of *physical enablement* is still very evident, and there remains a lack of knowledge and skills when it comes to caregivers knowing how to safely use an Enabling Care Approach to enhance the physical aspects of the life and experiences of an individual with a Learning Disability. These aspects include tone management, contracture management, standing programmes, and of course, 24hour postural management.

An example of this is that caregivers may be encouraged to be an advocate for an individual’s choices but may not be given the training and tools to be able to facilitate the practical elements of a task, in order that the person can actually maintain, regain, or even gain, functional abilities.

THIS TRAINING AIMS TO BRIDGE THIS GAP!



Linking an Enabling Approach to Safeguarding and the Mental Capacity Act Code of Practice

One of the major barriers to implementing an Enabling Approach to Care appears to have been a fear amongst Care Providers (and consequently their staff) that because they are responsible for keeping those they care for *safe*, they have to ensure that *all risks* are eliminated. This has resulted in a risk adverse culture, which is exacerbated by the fear of culpability and safeguarding litigation. The Mental Capacity Act⁽²⁴⁾ has helped to move this attitude forwards and, when establishing the most proportionate response and the less restrictive option, as well as considering the benefits and burdens of a decision, the following statement made by Sir Judge Munby puts what is now known as *positive risk taking* into a much more comprehensible light:

“The fact is that all life involves risk, and the young, the elderly and the vulnerable, are exposed to additional risks and to risks they are less well equipped than others to cope with. But just as wise parents resist the temptation to keep their children metaphorically wrapped up in cotton wool, so too we must avoid the temptation always to put the physical health and safety of the elderly and the vulnerable before everything else. Often it will be appropriate to do so, but not always. Physical health and safety can sometimes be bought at too high a price in happiness and emotional welfare. The emphasis must be on sensible risk appraisal, not striving to avoid all risk, whatever the price, but instead seeking a proper balance and being willing to tolerate manageable or acceptable risks as the price appropriately to be paid in order to achieve some other good – in particular to achieve the vital good of the elderly or vulnerable person’s happiness. What good is it making someone safer if it merely makes them miserable?”⁽²⁷⁾.

Mumby, 2007



Mental Capacity

What does it mean to have choice?

Every individual has the right to make a choice on how they live and to make decisions about their care, provided they have the capacity to make decisions.

A person who lacks capacity, should be supported to make each specific decision and if they are still unable to do so, a Best Interests decision must be made⁽²⁸⁾.

Assessing Mental Capacity: The 4-Question Test

Under the Mental Capacity Act, the following 4 questions need to be asked when assessing whether someone has the capacity to make a specific decision:

- Are they able to understand the information related to that decision?
- Are they able to retain the information? (Long enough to come to a decision)
- Can they use the information to make a decision?
- Can they communicate that decision (using any means)?

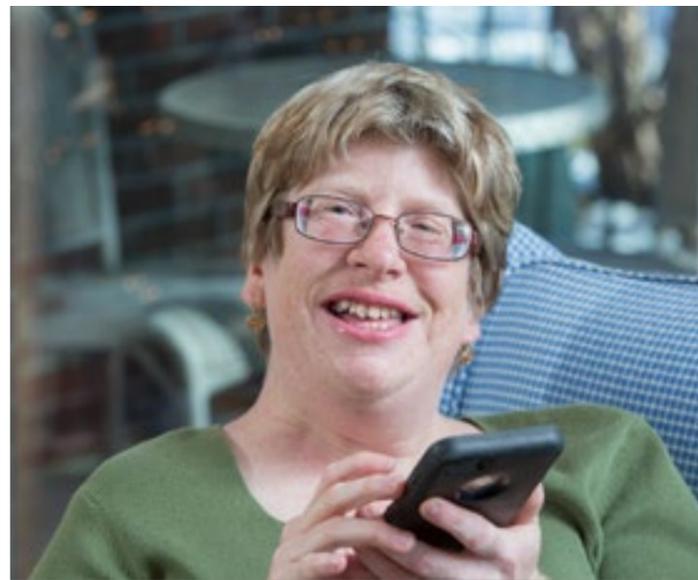
The answers to ALL the 4 questions MUST BE 'yes', for a person to have capacity to make a decision. As each decision may carry different risks, a person's capacity to make EACH decision MUST BE properly assessed by the person delivering the intervention/asking the question.

Decisions which are complex, or which require the caregiver to provide the individual with knowledge that is outside of their scope of practice, MUST BE referred to someone who does have the necessary knowledge. For example, for decisions about wearing a hand splint, this will be either a Occupational Therapist or a Physiotherapist.

What does it mean to make Best Interest decisions?

Making best interest decisions ensures that people are supported to make decisions for themselves when they lack mental capacity.

Even if people do not have the mental capacity to make a decision, they should always be at the centre of the decision-making process⁽²⁹⁾.



What does it mean to be empowered?

Staff should always look to empower individuals with knowledge skills and experience, by working together to improve quality of life within a person's communities.

Individuals should be helped to feel confident to make decisions about their own care and to manage their own health.

Individuals should also be supported to improve their health, so that they have as much chance as possible of leading the life they choose⁽³⁰⁾.

Why is being independent important?

A lack of independence can negatively affect a person's mental and social wellbeing, as well as their physical health.

The impact that being able to make choices and to live independently (with or without support) has, on a person's overall functioning, cannot be underestimated⁽³¹⁾.

Caregiver Tips:

NHS '5 Whys?'

The NHS '5 whys?' help staff identify the sources of an issue or problem⁽³²⁾. It encourages staff to start to question why individuals are not being enabled, by asking the question 'why?', until the underlying problem has been exposed.

- Write down the specific problem and then begin to ask why the problem occurs. Write this answer down.
- If the answer does not identify the problem than ask 'why?' again until you or those who you are working with agree that the problem's root cause has been identified. This may take more than 5 'whys?' or fewer.

Communication

Background:

A fundamental element of a Posture Friends and Enabling Care Approach is the relationship between people, which is built from meaningful communication. This is strongly influenced by how we say things, how we listen and by our non-verbal communication. These skills are relevant to the whole workforce and include communications between staff members ⁽²⁰⁾. The ability to communicate is essential to each and every one of us, as communication influences the way in which we can control our lives, make friends, be independent, make choices, and express our feelings, thoughts and wishes.

People with a learning disability can face challenges with communication. A learning disability can affect the way a person understands and as well as the way they express information. In addition, many people with a learning disability have some difficulties with speech, language, communication and/or sensory impairment, which may be hidden, masked or overlooked ⁽²⁰⁾.

It is therefore important to know what *good communication support* 'looks like', and what reasonable adjustments may be needed to achieve the best possible outcome.

It is essential to understand and value the way a person communicates, and to be aware of an individual's specific communication, speech, language and sensory needs and preferences, in order to communicate effectively ⁽²⁰⁾. It is also vital that we find out what is meaningful to an individual, not just about the activities they want to pursue, but also regarding how to communicate with that particular individual in a way that is meaningful and enabling. This is known as a 'personalised conversation' ⁽³³⁾.

It can be challenging to find the communication strategies that work for each individual, whether we are trying to encourage someone to participate in activity, or to simply give them confidence to continue with a task about which they lack confidence.

We must remember that communication involves taking into account a person's ability to make decisions and, whilst we are not permitted to 'coerce' someone, giving them *information* about a decision, enables them to make an *informed* decision. This is extremely important when people are unable to do things for themselves, as is often the case in a care environment.

For example, if you ask someone if they want a cup of tea and they decline because they want to wait for their daughter to arrive, and you do not communicate the information you have just heard that the daughter is not coming today, you have not enabled that person to make an informed decision about the cup of tea. *See the Case Study on page 25, which further emphasises this point.*

It is vital that we document the ways we have found to be helpful when communicating with each person, and that this information is shared on a Communication Passport. This should go with the person, for example, if they are admitted to hospital for any reason, as it will be of great help to the person if Health Professionals are more able to understand them and communicate with them more effectively.



Communication in practice

EVERYONE IS DIFFERENT, with different values, beliefs and interests

Using the *right* strategy/strategies, at the *right* time, to engage and motivate people to achieve their absolute highest potential, in whatever is *right* for them, is likely to make them (and us!) feel empowered.

Whether communication involves verbal or non-verbal language, there are some key concepts that need to be considered and understood.

Open and closed questions need to be used appropriately. For example, open questions are useful for gathering information, giving the person freedom to answer as they wish, and to ensure you are not unduly influencing their choices. They could be something like: "What would you like to eat for lunch today?". This could be too overwhelming in some situations, however, this for a person to answer. Instead, a series of closed questions here may be more appropriate. For example, "Would you like a hot or cold lunch?" followed by: "Would you like a sandwich or a salad?" and so on.

Behaviour that challenges:

It is important to remember that **all behaviour is a form of communication** ⁽³⁴⁾. People with a learning disability or Autism may have sensory integration challenges, or behavioural challenges, it is important to get to know each person and to work out the best way to respond in each situation*. Remember that behaviour changes may indicate that there is a problem, that the person is in pain, for example. It is quite common for changes in behaviour to be triggered by physical factors, such as constipation or urine infections, so factors underlying behaviour should always be investigated. The Disability Distress Assessment Tool** (DisDAT) ⁽³⁵⁾ is useful to identify distress cues in people who, because of cognitive impairment or physical illness, have severely limited communication.

*See the Additional Resources section in this resource booklet for useful links

**See HCPA Resource library

Tips for Communication ⁽³⁶⁾

Remember, all communication is meaningful, but you may need to work harder to understand and communicate effectively with specific individuals

Firstly, consider the following in terms of what seems to work best for the individual:

When and where?:

- Many people with a learning disability prefer face to face, and one to one communication
- Find a good place to communicate - somewhere without distraction
- If you are talking to a large group be aware that some people may find this difficult
- When using written communication, use bigger text and bullet points, and try to keep writing to a minimum. Also be aware that too much colour can make reading harder for someone
- Speak slowly and clearly when communicating on the phone, using easy to understand words

How?:

- Ask the person what method of communication works best for them
- Think about your tone of voice and body language, as well as the words you use
- Use accessible language
- Avoid jargon or long words that might be hard to understand
- Be prepared to use different ways of communicating
- Follow the lead of the person you are communicating with, follow their lead, and go at their pace
- Check you have understood correctly what a person has communicated before making assumptions
- Remember communication isn't just about talking, it's also about listening



You may also find these tips useful:

- Consider whether open or closed questions are more appropriate for each situation
- Check with the person that you understand what they are saying e.g. "The TV isn't working? Is that right?"
- If the person wants to take you to show you something, go with them
- Watch the person; they may tell you things with their body language and facial expressions
- Learn from experience - Be observant and ask others who know the person better for help if necessary
- Take your time, never rush communication
- Try drawing things or writing them down
- Be aware that some people find it easier to use real objects to communicate this is known as objects of reference
- Multimedia, such as pictures, photos and videos can also be very helpful for some
- Try using (or referring for assessment for) a voice output communication aid, such as a BIGmack, where appropriate
- Use gestures and facial expressions. If you are asking if someone is happy or unhappy, use facial expressions to reinforce what you're saying
- Think about training in Signalong or Makaton. These are languages/programmes that use signs, symbols and speech, giving a person different options when communicating*. These are both based on British Sign Language (BSL), and are used to support the spoken word

**See the Additional Resources section in this booklet for useful links for training for behaviour that challenges*



Communication - for specific interventions:

A considerable part of enabling happens before a task has started, through communication and motivation.

Before the task - Communication is used to:

- Build trust and rapport
- Empower
- Engage
- Encourage/Motivate
- Reassure
- Inform
- Give choice
- Set goals*

During the task - Communication can also be used to facilitate movement:

(this can be helpful even if the person does not appear to understand the words)

- Use verbal cues that are concise, short and clear, and remember that the timing of your cues makes a difference. This may improve movement patterns
- Use physical cues**- **light touch**, timing

After the task - Communication can be used to reflect and re-evaluate:

- Stop and reflect on your own interactions and conversation. Do you notice yourself doing any of the following?
 - ▶ **Making judgements about what you think a person should do or want**
 - ▶ **Wanting to fix things or pushing too hard**
 - ▶ **Trying to appease someone other than the individual e.g. a relative**
 - ▶ **Listening to respond, rather than to understand**
- Try to incorporate the following into future interactions/conversations
 - ▶ **Use active listening**
 - ▶ **Investigate - be curious about the person's wishes need and preferences**

**See page 71 for more details*

*** Please contact HCPA more information on the 'Posture Friends' Therapeutic Handling Training Module*

Case Study:

John, who has cerebral palsy, was due to have an appointment with the visiting Wheelchair Services Therapist. He was due to be issued with a new powerchair as his had broken three weeks ago and as a result, he had been requiring assistance to be pushed in an attendant-propelled wheelchair. On the day of his appointment, the in-house Therapy team asked a care staff member to go and get him for his appointment. The staff member returned stating that John was about to have his lunch and therefore had declined to come. When the Therapist questioned this decision, the staff member stated that it was John's choice, as he had capacity to make decisions. The Therapist stated that whilst that may be true, John had not been informed of the fact that this was the last appointment that Wheelchair Services had scheduled in for this visit to the home, and that if John didn't come to this appointment, he would need to wait until the next visit, in a month's time. The Therapist therefore asked the care staff member to see if John wanted to change his mind, based on this new information, and if so, to tell him that his lunch could be kept for him until after the appointment. John, of course, did decide to attend his appointment, as his independence was very important to him. He subsequently got his new powerchair (and he also got his late lunch!)



Posture and Positioning

This section of the resource pack aims to raise awareness of the impacts of posture on health and function, as this is a fundamental part of a Posture Friends and Enabling Care Approach. This resource pack draws on the currently available evidence.

Background:

Posture means 'the position (or alignment) of a person's body in any position, for example in lying, sitting or standing'.

An optimal posture is symmetrical. This means that it is identical on the right and the left sides of the body. It looks and feels stable, balanced and even. By contrast, an asymmetrical posture is different on each side of the body. For example, if the legs are both to one side, this is an asymmetrical posture.

A person without impairment is generally able to adjust the postural alignment of their body, and to balance with minimal twists and effort. A person with an impairment may find this difficult and may need:

- Assistance to achieve a position that is comfortable, and which allows optimal function, including being able to take a deep breath and cough⁽³⁷⁾
- Assistance to reposition themselves regularly to reduce the risk of pressure sores and pain⁽³⁸⁾
- Positioning aids or systems* to make the person's alignment as symmetrical as possible. This will prevent the person's posture from getting worse, and can, when done correctly, and gradually, **ACTUALLY IMPROVE POSTURE!**

Most of the available evidence in the UK on Posture and Postural Management in the Learning Disabilities sector is aimed at individuals with complex postural needs, who are unable to move or reposition themselves, and are therefore often managed by specialised Physiotherapists**. The name given to strategies aimed at improving and maintaining optimal positioning throughout the day and night is known as **24hour Postural Management**⁽³⁹⁾.

There is limited education for caregivers about the general principles that guide Postural Management, and it is important to remember that every person is different. The Physiotherapists who work in this sector, and in some cases Occupational Therapists, (particularly when there is a requirement for equipment), are the experts in this field, and a referral should be made to them if required. They will provide the caregivers with the guidance and training, which is specific to that individual.

*See Equipment Section on page 46

**Please note, for the purpose of this resource, the examples here focus on general things to consider in different postures. For advice regarding difficulties you may have concerning a specific individual's postural management, please refer to the Signposting Section in this booklet on page 72

Posture - In practice:

Getting lying posture right is the blueprint to improving any other posture⁽¹²⁾

Many people in receipt of care, for various reasons, spend long hours in a lying posture and difficulty with posture in sitting, is often the result of problems that started in lying. As soon as the hips and knees lose the ability to fully straighten in a lying position, the effects of gravity result in the knees adopting a non-optimal position:

- The knees lean towards each other, settling in the middle
- They may move together but to one side, (known as a windswept posture)
- They may fall open

These positions are non-optimal because they are likely to be asymmetrical. They are also self-perpetuating (they get progressively worse), more likely to cause pressure sores, as well as being uncomfortable or painful. This is the case in a person without impairment, and it is exacerbated by the presence of abnormal lower limb muscle tone, which is common in a person with PMLD. Any one of these non-optimal lower limb patterns will affect the alignment of the pelvis, and the rest of the body. An asymmetrical position of the pelvis can then lead to non-optimal alignment of the spine, which will in turn affect the position of the thorax (ribcage), shoulders, upper limbs, neck and head, as the body attempts to adapt, in order to remain stable and balanced against gravity.

In individuals with body shape distortion, body symmetry should be measured to gain a baseline from which improvements can be assessed. This may be done using the Goldsmith Indices of Body Symmetry⁽¹²⁾, which is usually measured by a specialist Physiotherapist.

It is important to note that some individuals, including many with dementia, may have damage to the parietal lobe of the brain. This is the area of the brain responsible for letting us know where our body is in space. It is extremely important to ensure that these individuals are well supported in lying with positioning aids or pillows, as this gives them 'reference points' and increases the sensory feedback they receive, making them feel much safer and more settled. This in turn reduces the chances of increased tone and contractures*

*For more detail on tone and contractures, see the Postural Management Challenges Section on page 50

Good (optimal) posture is important for being able to:

- Move
- Perform functional tasks
- Be independent
- Eat and drink
- Breathe, clear chest and stay well
- Access the environment
- Be free of pain

Poor (non-optimal) posture/body shape distortion can lead to:

- Reduced ability to move functionally, e.g. to lift an arm, to reach, to sit to stand
- Constipation
- Pressure on internal organs
- Pain
- Musculoskeletal problems: Muscle shortening/contractures/joint dislocation
- Pressure sores
- Emotional and psychological problems
- Breathing problems
- Swallowing difficulties and increased choking risk
- Chest infections, pneumonia and aspiration pneumonia
- Death
- Safeguarding cases
- *Also, the increasing inability to be repositioned going forwards, if body shape distortion gets worse*

The links between poor posture and breathing, chest infections and death:

- The most common cause of premature death in a person with a learning disability is a chest infection ⁽⁴⁾ and there is a direct link with posture ^(17,19)
- A cough is required to 'clear' our chest (upper airways). We need to take deep breaths in, in order to cough. Poor posture can impact upon a person's ability to take a deep breath, and therefore if an individual is unable to take a deep breath, they may be unable to generate a cough. This puts them at a greater risk of developing a chest infection:

Better posture = deeper breaths = less chest infections = less risk of death

- Swallowing difficulties (dysphagia) are a major cause of aspiration pneumonia. Dysphagia was highlighted by the 2018 LeDeR report as being one of the most common long-term conditions experienced by people with a learning disability, and aspiration pneumonia was found to account for 16% of reported deaths ⁽³⁾. Swallowing difficulties are made worse by poor postural alignment
- The link between positioning and pressure sores is widely understood in the Health and Social Care sectors:

Better postural management = less pressure areas = less infection risk = less risk of death

- The link between deterioration/death and potential safeguarding cases (and costs involved in time spent on safeguarding processes) is very clear

In terms of Enabling Care:

- The links between pain and quality of life, improved function and independence, are also clear

Key principles behind the National Postural Care Strategy ⁽¹⁹⁾

- Body shape – With the right support, body shape distortion is **NOT** inevitable
- An ordinary life – We all create our own kind of ordinary, whether that is having a family, going down the pub, going on holiday etc. Having good postural care means we are more enabled to have these ordinary, everyday opportunities
- Human rights – We all have human rights. If our bodies are left to twist out of shape, causing us pain when we sit in our wheelchair or pain when we lie in bed, it may be an infringement of these rights
- Mental wellbeing – Having good postural management not only leads to physical health benefits, it also means mental wellbeing improves
- Accountability – Postural care is a silent killer and yet there are no clear lines of accountability

Expected impact of upskilling in this area:

- Improvements in quality of life, function and participation, making it easier to support people with activities of daily living
- Greater caregiver understanding and confidence in postural issues, resulting in increased comfort and better postural alignment
- Better caregiver ability to spot signs of deterioration
- Better management of muscle tone problems (e.g. spasticity and contractures)
- Reduced numbers of respiratory infections, in individuals with a history of frequent chest infections, and overall
- Reduced unnecessary hospital admissions that are due to a chest infection
- Reduced pressure sores and reduced complications arising from them
- Reduced agitation and pain
- Improved caregiver knowledge and skills in moving and handling practices, resulting in a less physically demanding workload
- Improved relationships between Care Providers and Community Therapists, and other Community Teams
- Improved staff job satisfaction
- **A reduction in mortality rates in people with a learning disability receiving care**

Why is this not already being addressed?

- Lack of awareness – people are often unaware of the consequences of body shape distortion
- Lack of resources – not all areas have a postural care service and Community Therapy services are stretched
- Challenges in implementing postural care programmes– particularly with night-time positioning
- Hospital admissions – 'posture and positioning' is not generally recorded as a cause of a chest infection or pressure sore
- Lack of consideration of postural care as a safeguarding issue
- Lack of research – ongoing need for evidence that demonstrates 'cost-effectiveness'
- Commissioning considerations

Staff/Relative Posture Self-Awareness Activities

1a) Check yourself in a sitting position

- Is your pelvis level?
- Are your shoulders level?
- Do your arms feel an equal weight when you lift each arm up separately?

1b) Now check yourself in a 'crooked' position

(you can do this by shifting so you are sitting more on one side of your bottom)

- Is one shoulder higher than the other?
- Is your trunk shorter and squashed on one side?
- Is your low back or neck twisted?
- Do your arms feel an equal weight when you lift your arm up, or does one arm feel heavier to lift?
- How long can you stay in this position before you are uncomfortable and want to move?

2a) Sit in an upright sitting position

- Stand up without using your arms.
- Notice whether this feels easy or difficult.

2b) Now sit in a really crooked sitting position

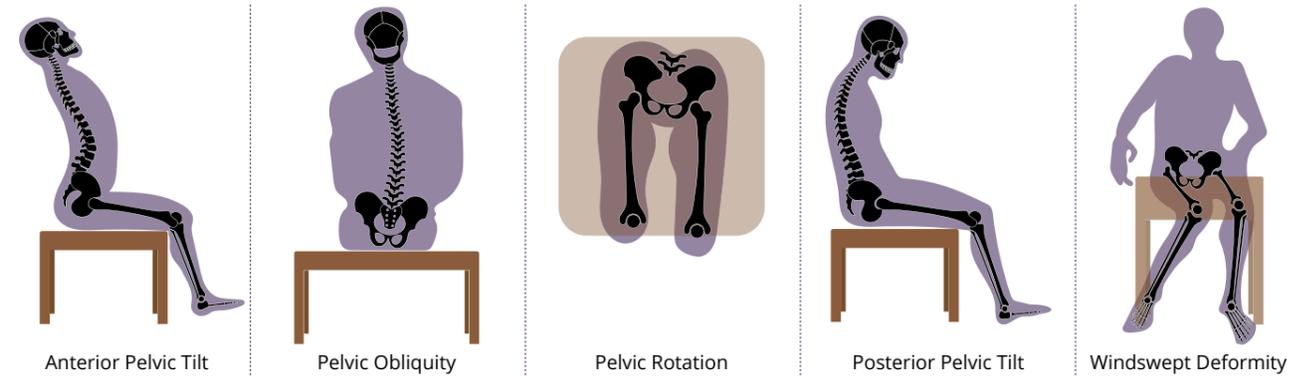
- Stand up without using your arms.
- Notice whether this feels more difficult.
- Can you actually do it without repositioning yourself?

3a) Sit in an upright sitting position again

- Blow up a balloon.
- Notice whether this feels easy or difficult.

3b) Now sit in a really crooked sitting position

- Blow up a balloon.
- Notice whether this feels more difficult.
- Do you need to take extra breaths or is it harder to reach the same volume of air in the balloon?
- What you are likely to have felt when you did the above activities?
- Was that it was more difficult to do a functional activity from a crooked or non-optimal position?



Remember:

- People without impairments move frequently, usually without even thinking, if they are becoming uncomfortable
- Imagine you are in a crooked or uncomfortable position for a long period of time. You may be in pain as well as being less able to carry out functional activities
- You may also feel pain when you eventually move or are assisted to move. This may cause you to resist being moved. Imagine if, on top of this, you cannot express how you feel!
- Support good posture at mealtimes, as this will improve a person's ability to swallow effectively
- The longer a person's joints are in a poor position, the more difficult their position will be to correct, therefore PREVENTION of deterioration is KEY
- It is not always possible to achieve 'perfect' alignment, but it is definitely important to understand that deterioration can be minimised by good postural management
- Specialist PHYSIOTHERAPISTS are the experts in this field. ALWAYS refer to them for advice
- For people with complex postural needs, ensure that photos of positioning aids, equipment and guidelines are revised as part of the annual review of their health needs, or sooner if necessary



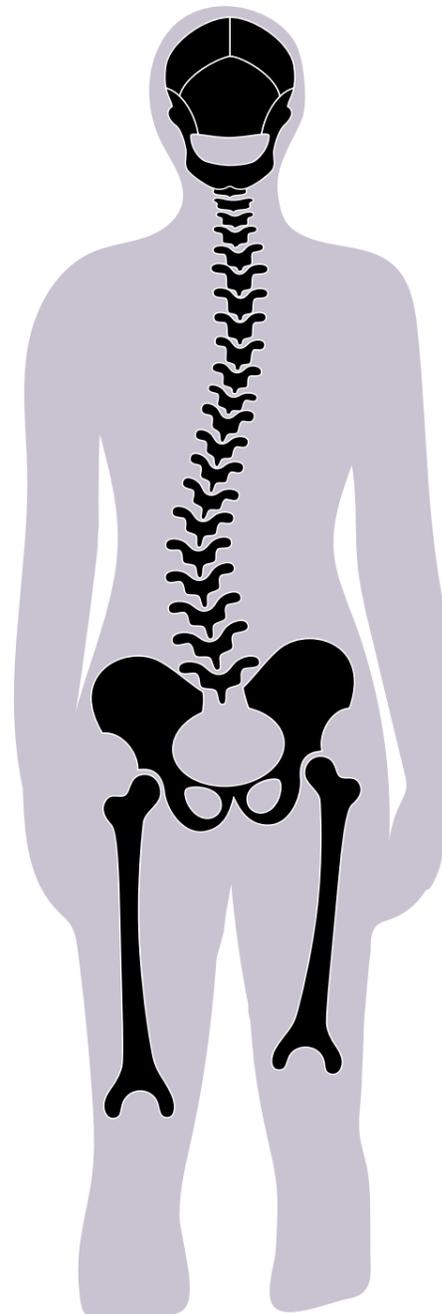
Alignment

In order to optimally position people who cannot move themselves, it is important for caregivers to understand what 'good positioning' looks like.

There is a neutral position for each joint or area of the body, and the position of each part of the body affects other body parts. The positions described here are those which are optimal in a static (still) position. Joint position is affected by many things, but the main consideration for the purpose of this resource is that shortened, and/or high tone muscles dramatically affect the position of the joints.

Alignment during movement is complex, so is beyond the scope of this resource booklet. It is important, however, to have an awareness that non-optimal static postures are likely to adversely affect functional movement.

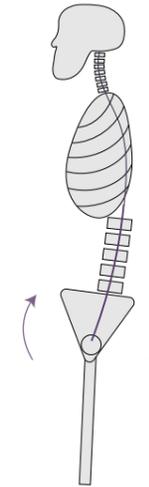
Non-optimal Alignment



This picture shows how the non-optimal position of the pelvis affects the spinal curves and the position of the lower limbs.

The Pelvis

Optimal = not tilted forwards, backwards, rotated or 'up on one side' (known as a pelvic obliquity). If the pelvis is not in neutral, it is more difficult to correctly align other joints in the body. This is the case in standing, sitting or lying.



Posterior Pelvic Tilt Posture

As the pelvis rotates backward the lumbar spine adopts a more flexed (flattened lumbar curve) position.

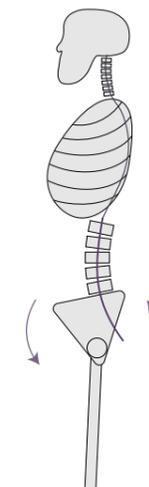
The hips are in an extended position.



Neutral Spine Posture

In this position the pelvis is close to level and the lumbar spine has a slight inward (lordotic) curve.

The hips are in a neutral position.



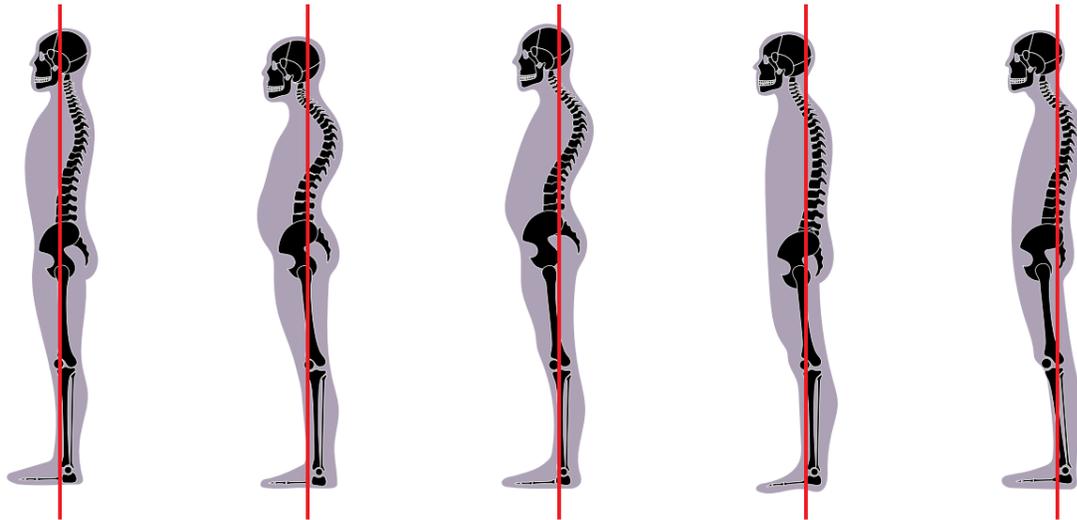
Anterior Pelvic Tilt Posture

As the pelvis rotates forward the lumbar spine adopts a more extended (hyper-lordotic) position.

The hips are in a flexed position.

The Spine

Optimal = with the normal S-shape curves when looking from the side, and with no curves when looking from in front or from behind.
This is the case in sitting, standing or lying.



IDEAL

If a line is drawn down from the ear, to the middle of the shoulder, to the outside prominence of thigh bone (greater trochanter), to the knee and then to the outside of the ankle bone, it is a straight line, with no deviations.

KYPHOSIS-LORDOSIS

An exaggerated curve of the upper back, makes it look "rounded", and an exaggerated curve of the low back makes it have more of a dip inwards.

LORDOSIS

Similar to the Kyphosis-lordosis posture, with a less exaggerated curve in the upper back, and more of a forward head position.

FLAT BACK

Flat back posture characterised by the lack of natural curvature of the spine therefore causing a stoop forwards.

SWAY-BACK

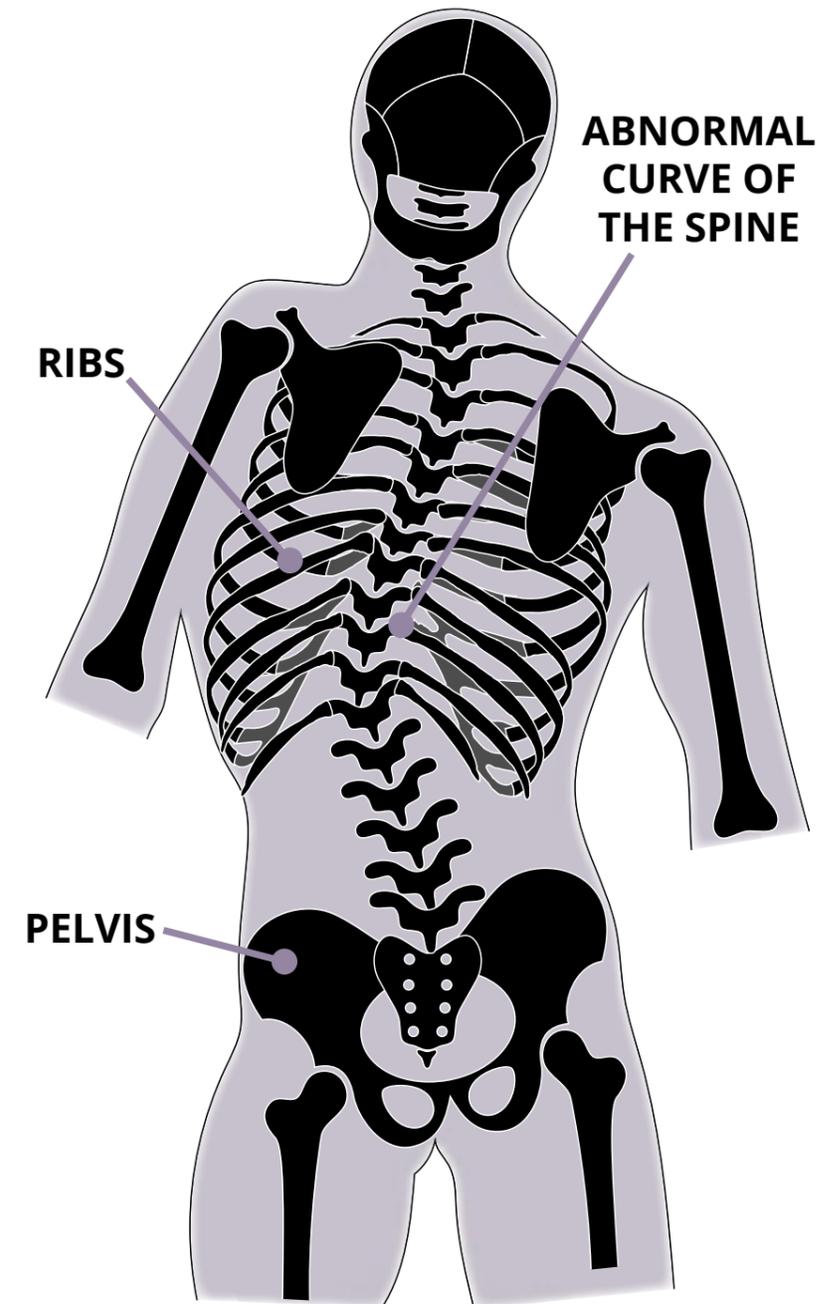
Characterised by the pelvis tilted upwards at the front and the hips leaning forwards, with the upper back leaning back behind the hips and the head in a forward position.

Abnormal curves show as different postures such as those seen in this picture. The neutral posture here is the 'ideal' one.



Scoliosis

A scoliosis may cause one shoulder to look higher than the other from in front or behind or it may cause the trunk to rotate (twist).



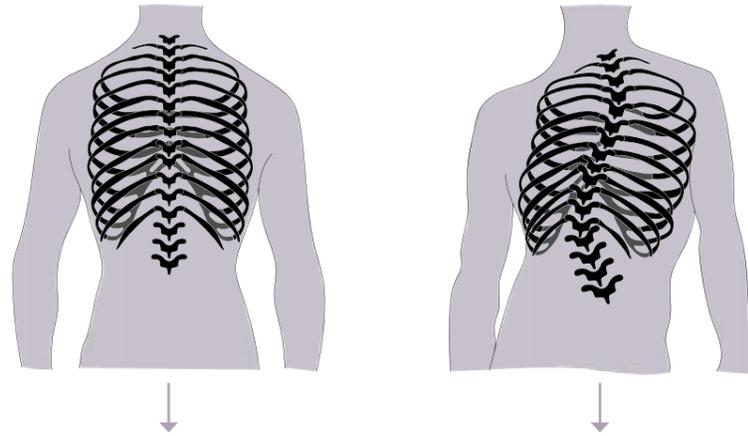
SCOLIOSIS

Thorax (Ribcage)

Optimal = Evenly spaced ribs on each side, with no rotation or side bend.

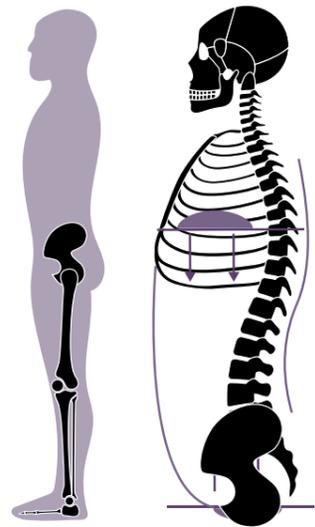
If the spine has a scoliosis, the ribcage will always be affected. This reduces the ability of the lung on the 'squashed' side to expand

This is the case in standing, sitting or lying.

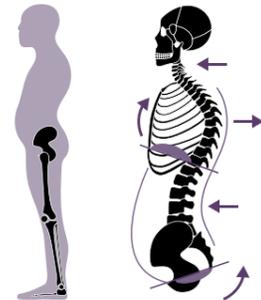


Optimal Postural Pattern

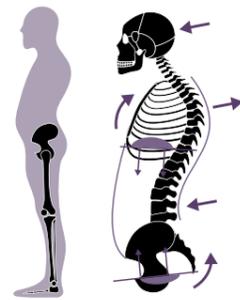
Non-Optimal Postural Patterns



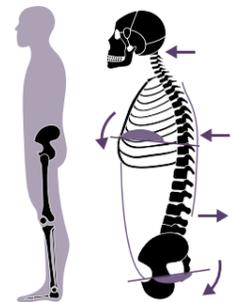
Ideal Posture: Spine upright, chest properly positioned above the pelvis, diaphragm horizontal, pelvis in neutral position



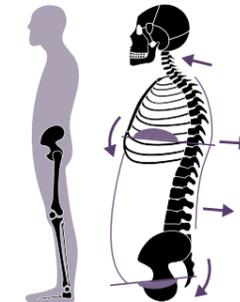
Kyphosis-Lordosis: An exaggerated curve of the upper back, makes it look "rounded", and an exaggerated curve of the low back makes it also have more of a dip inwards.



Lordosis: Similar to the Kyphosis lordosis posture, with a less exaggerated curve in the upper back, and more of a forward head position.



Flat back: Characterised by the lack of natural curvature of the spine therefore causing you to stoop forwards.



Sway-back: Characterised by the pelvis tilted upwards and the hips leaning forwards at the front, with the upper back leaning back behind the hips and the head in a forward position.

Hip

Optimal = feet 'hip width' apart (this means feet in line with the hip sockets, not in line with the outside of the legs). The femur should not be turned inwards (medial/internal rotation) or outwards (lateral/external rotation), therefore knees and feet face forwards (and also do not turn in or out).

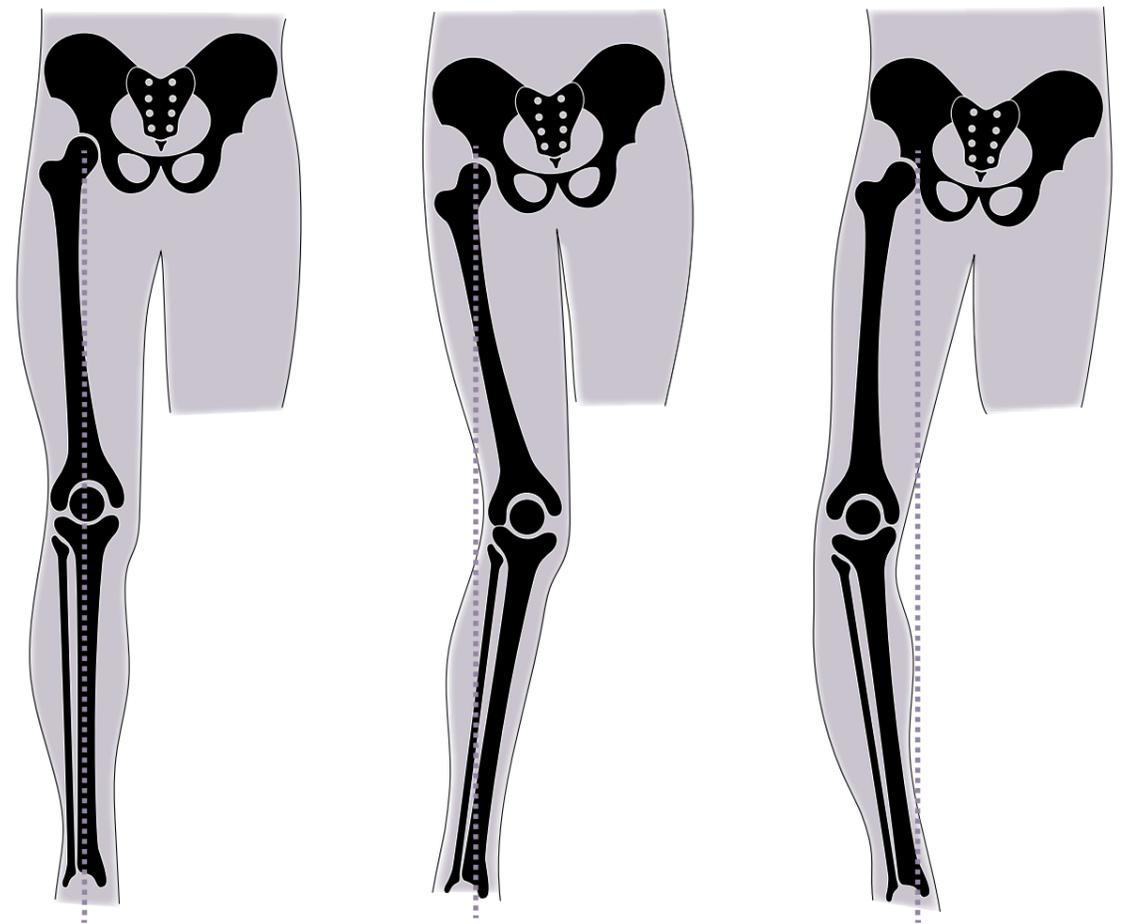
This is the case in standing, sitting or lying.

The hip and femur (thigh bone) is mainly affected by the position of the pelvis, but it in standing can also be influenced by the position of the foot.

Knee

Optimal = in line with hip and foot, not medially/internally rotated (turned inwards) or laterally/externally rotated (turned outwards).

This is the case in standing, sitting or lying.



Optimal

Valgus

Femur (thigh bone) rotated inwards

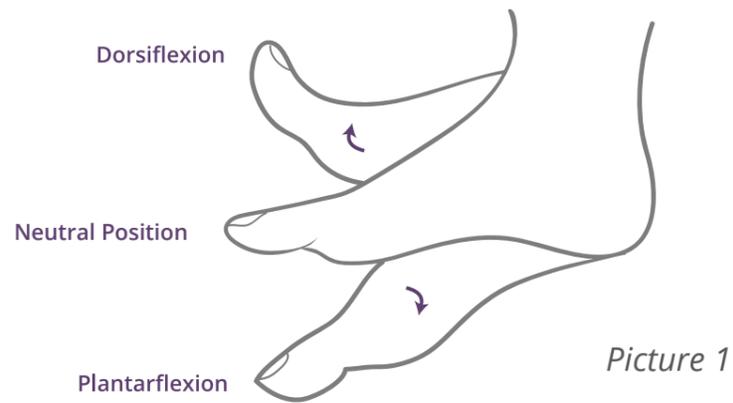
Varus

Femur (thigh bone) rotated outwards

Ankle

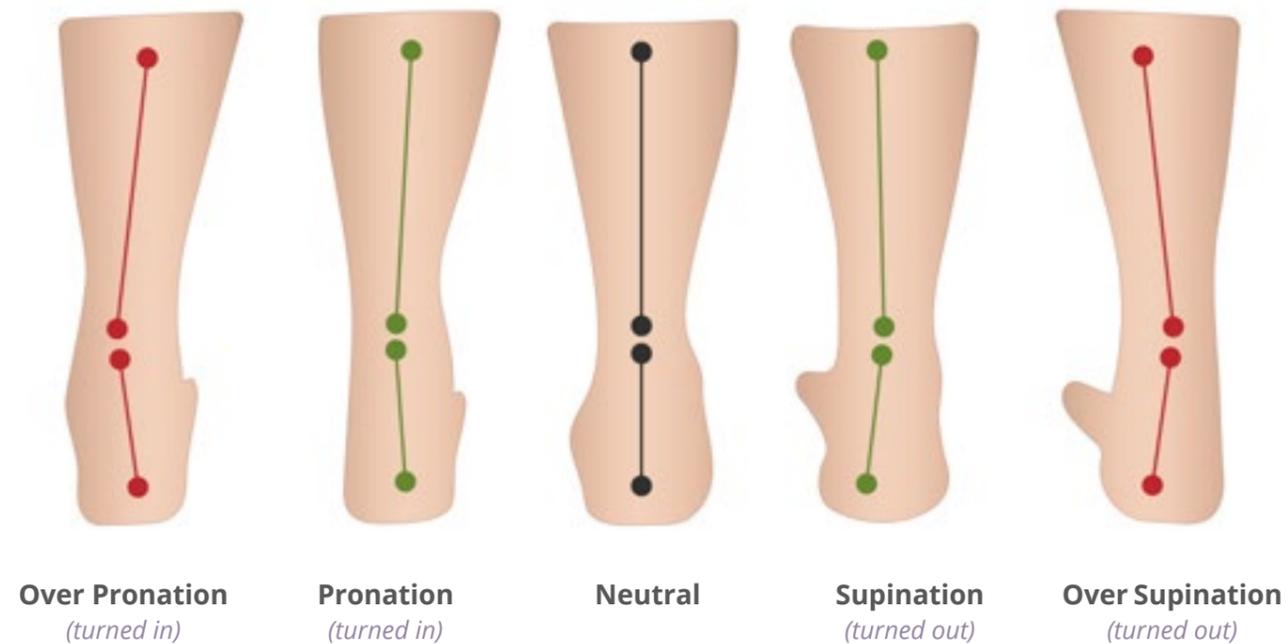
Optimal = with the foot at right angles (90 degrees) to the lower leg i.e. not plantarflexed or dorsiflexed (picture 1), not inverted (supinated hindfoot, picture 2) or everted (pronated hindfoot, picture 2), and not rotated inwards or outwards.

Pillows between the soles of feet and end of bed are extremely important if a person is in bed for any length of time, for example if they are unwell. This is to prevent shortening of the calf muscles, which may prevent standing, when the person becomes well again. Splinting* is often necessary to maintain joint range if the person has abnormally high tone (hypertonia). Please note: Pillows should not be placed between the back of the heels and the mattress, as this may compromise the pressure relieving property of the mattress.



Picture 1

Picture 2



Arm (Upper Limb)

Optimal = the thumb should point forwards or upwards i.e. shoulder and upper arm bone (humerus) are not rotated inwards (medial/internal rotation) or outwards (lateral/external rotation).

This is the case in standing, sitting or lying.

The hand should be in line with the arm at the wrist, i.e. not bent towards (or away from) the inside of the forearm.

The hands are often in a non-optimal face down (pronated) position, which turns the shoulders inwards and in turn can cause the thoracic spine to 'round' (kyphosis) and the head to move forwards on the neck. A 'thumbs up' position is a better neutral resting position.

The shoulder can often become painful, therefore it needs careful positioning and gentle, supportive handling.



*See Postural Management Challenges – Splinting in section 5 of this resource booklet for more details

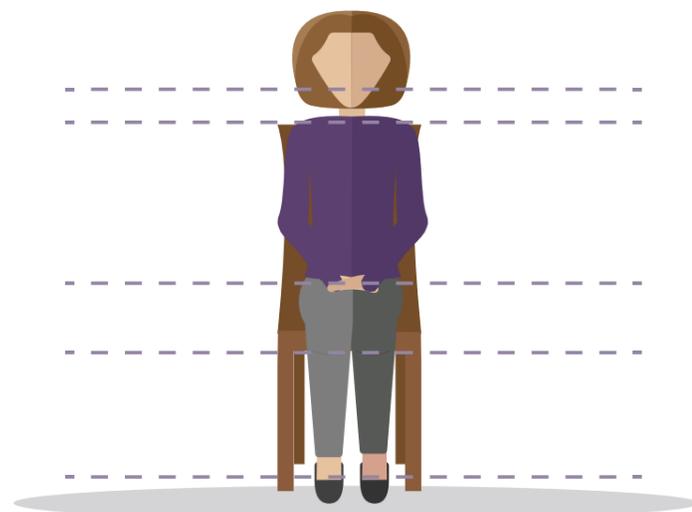
Staff/Relative Posture Tips:

Sitting posture

Use **PEAK** to check the sitting posture of an individual:

Is the person evenly positioned?

- P** - pelvis in a neutral position
- E** - equal weight on both buttocks
- A** - 90° angles at hips, knees and ankles
- K** - knees facing forwards

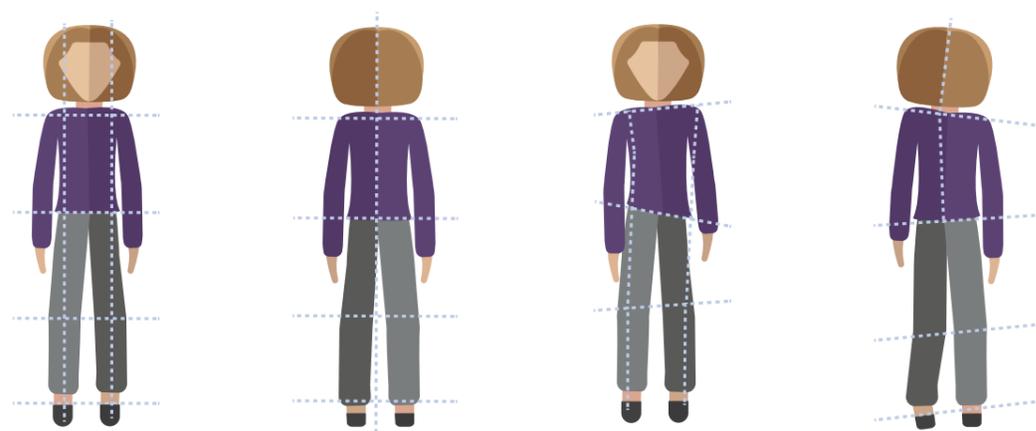


1. If not, can you improve it by repositioning them? (This may involve re-hoisting)
2. OR, do you need professional advice from a Physiotherapist?
3. Reposition OFTEN
Ensure joints are in supported in good alignment, with appropriate equipment/pillows where necessary
4. The pelvis is the most important point to look at to check whether a person is sitting well, as, when corrected, this will often also improve the alignment of the rest of the body

The appropriateness of a person's seating (chair, armchair or wheelchair) is of utmost importance and in many cases may require a referral to a Physiotherapist or Occupational Therapist or to Hertfordshire Wheelchair Services for an assessment*

**See Equipment - section 4 of this resource booklet for more details*

Standing posture

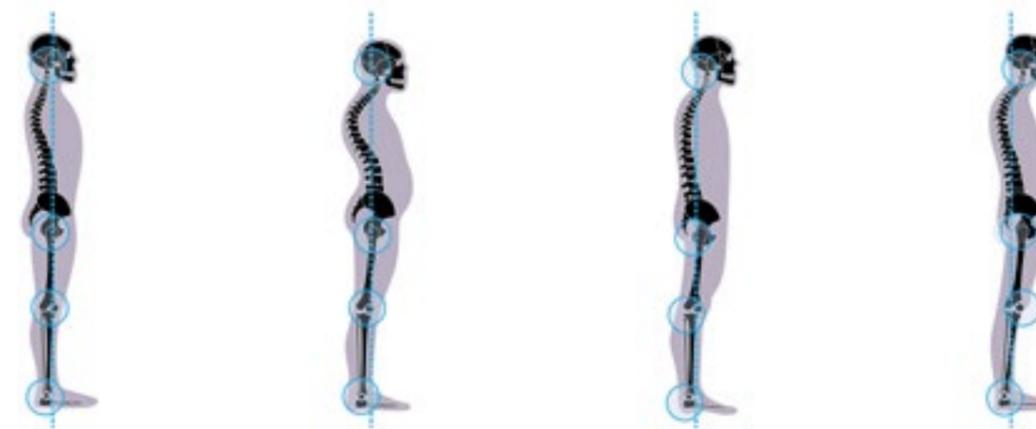


Correct Functional Alignment

A pain-free body: All major joint groups are aligned

Dysfunctional Alignment

In the foot, for example, a collapsed arch could cause pain in the entire body



IDEAL

KYPHOSIS-LORDOSIS

FLAT BACK

SWAY BACK

When there is an imaginary single straight line from the middle of the shoulder, through the hip and knee to the ankle

Kyphosis is the exaggerated curve of the upper back. While lordosis is the exaggerated curve of the lower back.

Characterised by the lack of natural curves of the spine causing a forward stoop.

Characterised by the hips leaning forward of the feet, and the forward head position.

Good alignment in standing:

Ideal alignment is not easy for any of us to achieve with our own body, as muscles and joints adapt over time and most of us have non-optimal postural habits.

It is even more difficult to change posture in others, especially when there is limited understanding of caregivers on *how* to correct things. The most a caregiver can do is to give verbal reminders where appropriate, but this may of course be limited by the individual's ability to understand verbal prompts. A Physiotherapist may be able to improve a person's alignment with manual therapy, but this is NOT the remit of an unqualified person.

Good standing posture is:

- Is best achieved from a good sitting position
- Is best achieved if techniques that follow 'normal movement patterns' for sit to stand are used.
- These include:
 - ▶ Starting from a neutral (not a crooked) pelvis position
 - ▶ Ensuring there is equal weight on each foot
 - ▶ A shuffle forward (facilitated if unable independently*)
 - ▶ Feet position - hip-width apart, ankles slightly behind knees
 - ▶ Slight anterior pelvic tilt (using facilitatory touch to achieve this*)
 - ▶ Encouraging a 'push up' using hands on chair arms
 - ▶ A forward lean - using momentum, and "ready, steady, stand" cue
 - ▶ Encouraging focus forward and upwards
 - ▶ Ensuring stability in standing (with aid if using one) - this may require verbal prompts to keep 'knees straight', or to 'straighten up' at the hips
 - ▶ Use gentle handling techniques*
 - ▶ Give the appropriate level of assistance (too much assistance means no opportunity for the person's body to engage, practise and improve)
 - ▶ Once in standing, think about safety, give time before mobilising

**Please refer to HCPA's Posture Friends Tier 2 Therapeutic Handling Module*

Positioning in the lying posture

A lying posture can be necessary during the day, as well as at night.

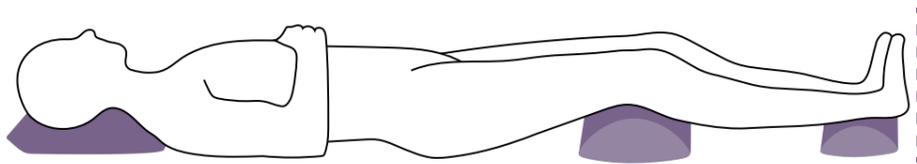
In order to reduce the negative effects of poor positioning, and the consequent likelihood of worsening alignment, the body should be positioned in a symmetrical position, (or as near to symmetrical as possible). Additionally, all joints should be positioned in as near to 'neutral' alignment as possible.

Neutral joint alignment is the body's biomechanically 'correct' alignment. When we are in neutral alignment, we are in the position in which there is the least amount of stress on our joints.

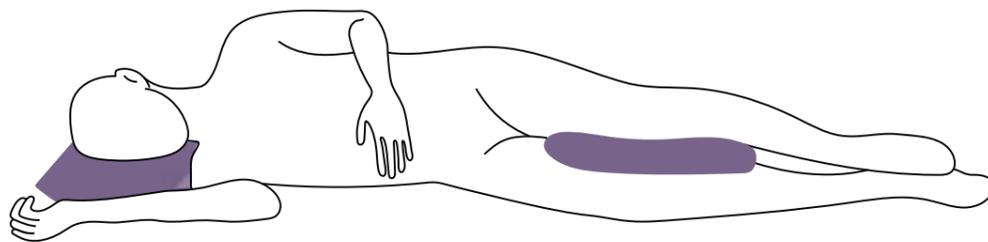
Some people with a learning disability, particularly those with complex physical disabilities, who cannot reposition themselves, (such as individuals with PMLD), may require careful positioning of all their joints. They may also require specialist equipment to support them in a more optimal position*. There are a variety of positioning aids* which can help. However, as everyone is different, and there are advantages and disadvantages of each piece or type of equipment, an assessment by a specialist Physiotherapist or Occupational Therapist is usually required.

As discussed on page 27, remember to add support** as needed, to optimise positioning in any position, and to provide 'reference points' for individuals who have a sensory impairment, for example, with an individual with PMLD or dementia.

Supine (face up) lying



Optimal Side Lying Posture



Side-lying is not a symmetrical posture, so it is likely to cause a deterioration in joint alignment, and consequently more difficulty with other postures. It should be avoided, unless it is for safety reasons. For example, if an individual has a chest infection, they may have better oxygen saturations in side lying, or they may require side-lying for pressure relief. Also, if a person has had a stroke and has hemiplegia (one sided-weakness, it may benefit them to lie on each side, as each side has advantages and disadvantages*

***Always ensure a risk assessment is carried out and a referral is made to an AHP, such as a Physiotherapist or Occupational Therapist for a person with complex needs. See Table on Signposting on page 77 of this booklet*

**See Sleep Systems in the Equipment Section on page 45*

Equipment

Equipment for Postural Management

This is a complex area and a person's specific needs are best assessed by a specialist Physiotherapist or Occupational Therapist, who have experience working with people with a learning disability.

Whilst it is beyond the remit of this resource booklet, funding for equipment is usually on a case-by-case basis.

CECOPS (Community Equipment Code of Practice Scheme):

- It is a user-led, independent, not-for-profit certification and standards body, aiming to raise the standard of all assistive technology related services across the UK.
- It is the only standards body representing all assistive technology services including, for example, community equipment, wheelchair and seating services, telecare, telehealth and communication aids.
- It is also unique in that it covers commissioning, provision and clinical aspects of services.
- It is formally approved by regulators and professional bodies including the Care Quality Commission (England), The Health and Safety Executive and the Association of Directors of Adult Social Services.
- The CECOPS official guide, the Code of Practice for Disability Equipment, Wheelchair and Seating Services is useful reading for all commissioners, providers and clinical staff involved with these services.

Standing Equipment

Standing equipment varies depending on the amount of support a person needs. For example, a tilt table with complete support is needed for someone with no independent standing balance, whereas an Oswestry type frame, which gives less upper body support, may be used to help improve a person's trunk control.



Seating and Wheelchairs

Whether for mobility or relaxation, it is extremely important that any type of seating provides appropriate support, and aids good alignment.

There are many different types of wheelchair and, other than for a standard wheelchair, it is the job of a qualified Therapist to assess for and to prescribe the most appropriate wheelchair, with the right support for each specific individual. A referral to Hertfordshire Wheelchair Services is advised for any wheelchair requirements.

Someone with a postural impairment (especially a person who cannot adjust their own position) may need bespoke moulded seating, that is constructed specifically for their body shape. Others may need special accessories to promote good alignment, for example a lateral support at the chest for good trunk alignment, or a pommel between knees to limit the knees pulling together, such as can be the case with strong inside thigh muscle (adductor) tone.



Sleep Systems

Sleep systems are used to support people who cannot move themselves voluntarily into optimal alignment in bed, and to help protect them if they have uncontrolled movements whilst resting. They help limit injury, tone, contractures, and the development of body distortion. There are many different types available, some more rigid, some softer e.g. Symmetrikit, Simple Stuff Works.



Equipment for Transfers and Mobility

Background

Physiotherapists are the key Allied Health Professional (AHPs) to involve regarding the appropriateness of a mobility aid or positioning, whereas Occupational Therapists are the key AHPs to involve regarding the appropriateness of a most other pieces of equipment that will improve function.

These professionals have been trained to weigh up the advantages and disadvantages of each piece of equipment and are therefore able to assess an individual's needs appropriately. Since caregivers are in regular contact with their individuals and often know them very well, they are often the people to notice when the individual's needs change, and can signpost when required (see the Signposting section of this booklet on p72).

In Practice:

Although equipment that has been issued to an individual may have been appropriate for their needs at the time it was issued, it may be that it is no longer appropriate.

For example, someone who has recently been discharged from hospital with a Rotastand for transfers, may improve, and be able to sit to stand without the equipment a few days after returning home. In this case, continued use of the Rotastand may in fact be *disabling*.

Two things are important here:

- Firstly, the individual's needs should be reviewed precisely at the point that their needs change, as delaying this could mean that their opportunity to improve is missed
- Secondly, someone (usually a member of care staff), needs to have a *questioning approach* to the possibility that the individual has the potential to improve

This means that the care staff may also need to try encouraging the individual to sit to stand to ascertain whether there is any potential for improvement.

This type of scenario needs to be risk assessed, to ensure that the benefits of being more physically active outweigh the risks of falling.

The benefits of being more active almost always outweigh the risks of not being active ⁽³⁹⁾.

Therefore, providing the activity is carried out as safely as possible, with strategies in place to minimise the risk of falling, this is what is known as Positive Risk Taking.



Caregiver Equipment and Mobility Aids Tips

- For sit to stand practice, this may involve having two members of staff for safety, (NOT to lift). For mobility practice, this could involve 3 members of staff (one either side and one close behind with the wheelchair)*
- HCPA's Posture Friends Tier 2 Module 5 on Therapeutic Handling covers practical techniques to enhance your ability to get people to get up on their feet.
- Did you know that the use of the arms to *pull up* from a chair, unless the only option, may *disable* someone as it promotes the use of arms *not* the legs. Our normal movement pattern for sit to stand is to use our arms and our legs to *push up* from the chair. Consider whether the person using a Rotunda or a Rotastand e.g. on return from hospital after being unwell, could practise sit to stand using a pushing motion instead of pulling*.
- Consider also, the scenario where someone who can walk to the bathroom is always transferred in a wheelchair. Is this person likely to retain their ability to mobilise or are they likely to lose it?

* Always ensure a risk assessment is carried out and that an AHP, such as a Physiotherapist or Occupational Therapist (OT) is consulted if you are in any doubt. See Table on Signposting on page 69 in this booklet

Caregiver Equipment and Mobility Aids Tips (cont)

Ask:

- Would a piece of equipment or a different piece enable someone to perform a task more easily, more independently?
- Carry out regular equipment audits: Is it safe and in good working order? Was it prescribed for the individual who is using it? Does it appear safe? Does it enable or disable the individual?
- Review equipment regularly – keep an open mind and consider whether the person can improve.



Mobility Aid Selection

1. Comes from experience and competence.
2. Weighs up safety versus independence.
3. Is a complex decision-making process and complex assessment

Therefore, currently, the prescription of mobility aids needs to be by a specialist Physiotherapist or Occupational or an appropriately qualified Moving & Handling Assessor.

Your role is:

- To spot when someone needs a mobility assessment and refer as soon as possible to a specialist Physiotherapist.
- To carry out regular audits on Mobility aids – are they safe and in good working order? Were they prescribed for the individual who is using them? Do they appear safe? Do they enable or disable the individual?
- Consider, for example, referring to Hertfordshire Wheelchair Services for a self-propelling wheelchair, if an individual can use their arms and you think they are cognitively able to use one. Always consider whether the person with a learning disability has the cognition to safely use the equipment before making a referral.



Postural Management Challenges

Even with the appropriate knowledge and skill level, and/or appropriate equipment, there are many things that may affect optimal alignment in a person with a learning disability. The following are examples of some of the challenges.

Abnormal Tone

Tone is the resistance of muscles to passive stretch or elongation, basically the amount of tension a muscle has at rest. Abnormal tone is caused by a disruption of the messages (nerve impulses) from the central nervous system to the muscles, which occurs in conditions such as Cerebral Palsy, Multiple Sclerosis, Stroke and Brain Injury. Abnormal tone may mean that it is difficult to position the pelvis, the thorax, head and neck, limbs, hands or feet in good alignment either because of high tone (hypertonia) or low tone (hypotonia)⁽⁴⁰⁾.

- **Hypertonia:** Increased tightness/muscle tone and reduced capacity of the muscle to stretch caused by damage to the motor nerve pathways in the central nervous system. This results in the limbs being difficult to move and the joints becoming stiff and contracted*. Untreated hypertonia can lead to loss of function and deformity. Treatment can include physiotherapy and/or occupational therapy, splinting* or medication, such as Tizanidine or Baclofen. Botulinum Toxin-A injections into specific muscles, or in extreme cases of lower limb contractures, intrathecal Baclofen pumps can also be an option⁽⁴¹⁾.

Tips to reduce tone

- ▶ Supporting a limb with pillows, and other suitable equipment, increases the base of support, which can help reduce tone. Care must be taken, however, not to undermine the effectiveness of pressure relieving surfaces, such as air mattresses, by, for example, placing a non-pressure relieving surface under a heel
 - ▶ It is important to use *gentle handling*, as this helps to reduce tone and tonal spasms
 - ▶ It is important to know that certain things further increase tone in some individuals. These include: anxiety, fear, pain, low external temperature, bowel or bladder sensations (for example pain from a urine infection (UTI), or constipation), skin (pressure sores), injury, systemic illness, tight clothing or catheter bags, medication changes, and seating/mattress changes
- **Hypotonia:** Decreased muscle tone. Healthy muscles are never fully lacking tone as they are constantly receiving nerve impulses from the brain. They therefore retain a certain amount of tension and stiffness (muscle tone) that can be felt as a slight resistance to movement. For example, a person relies on the tone in their back and neck muscles to maintain their position when standing or sitting up⁽⁴²⁾. *see Contractures part of this section

Tips to increase tone

- ▶ Supporting a limb too much with pillows, or other equipment, increases the base of support, and may further reduce tone. Reducing such support, as long as it is comfortable and safe for the individual, may increase tone, and therefore activity. These issues are best discussed with a specialist Physiotherapist or Occupational Therapist
- ▶ It is important to know that certain things further decrease tone in some individuals. These include: being too warm, certain medications, lack of movement, and lack of sensory stimulation. These issues are best discussed with a specialist Physiotherapist or Occupational Therapist

*see Contractures on page 52

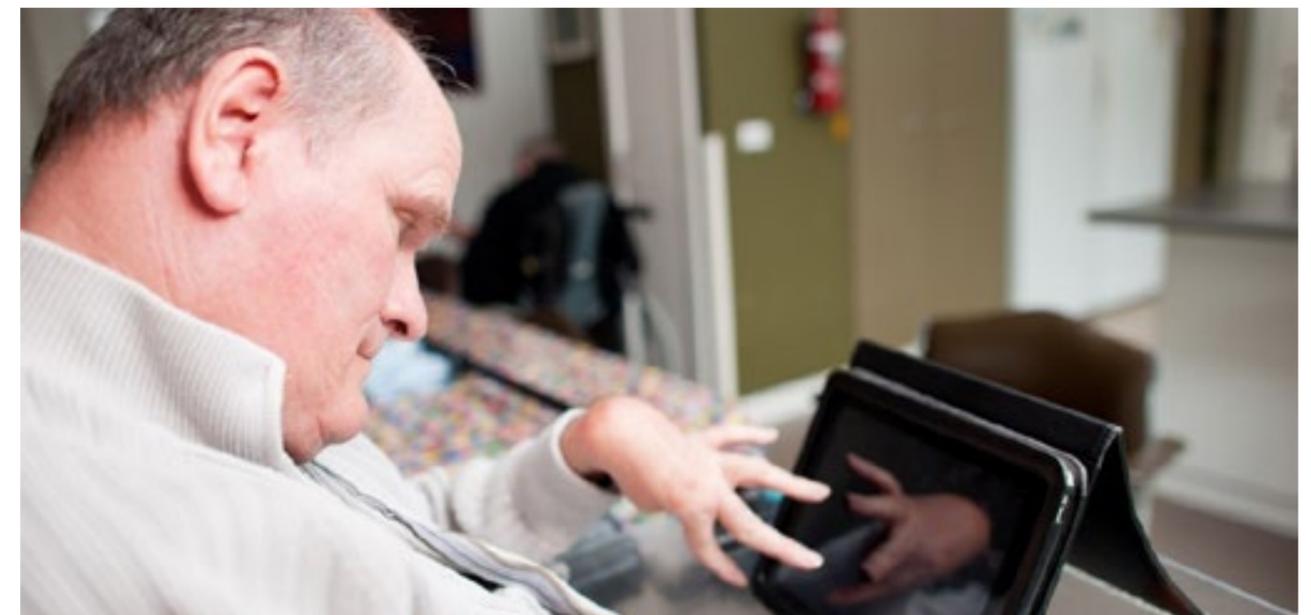
** see Splinting on page 53

- **Spasticity and Spasms:** Spasticity is a term that is often used interchangeably with hypertonia. However, it is a particular type of hypertonia in which muscles acquire a state of near constant contraction, or activity. Spasticity is defined as; a velocity-dependent increase in muscle tone that manifests with resistance to movement and involuntary muscle **spasms** and contractions. Muscle spasticity causes a loss of range of motion of the affected area and a loss of function. In the affected muscles, spasticity can also cause symptoms such as pain, stiffness, abnormal posture and joint deformities (contractures), as well as anxiety. Clinically, spasticity results from the loss of inhibition of motor neurons, in an individual who has damage to their brain or spinal cord. This ultimately leads to hyperreflexia, an exaggerated deep tendon reflex.

Spasticity is often treated with the drug Baclofen. Spasms are hyperactive reflexes, which give rise to sudden or uncontrolled (involuntary) contractions of a muscle or muscles, and which may cause a limb to kick out or jerk⁽⁴³⁾.

- **Repetitive Movements:** Movements that are either voluntary (sometimes a person may do these as a comfort measure), or involuntary. How to manage them depends on the cause.

Contractures



■ **Contractures:** A contracture is a common secondary complication of weakness and paralysis following nervous system damage and is defined as; a fixed limitation in passive range of joint movement. The presence of features like spasticity play a role, in the loss of range of movement. Contracture formation is complex and multi-factorial and who gets affected and why, is not yet understood ⁽⁴⁴⁾.

- ▶ Decreased range of movement can lead to a loss of function, both active and passive. Active function is the performance of a functional task by the individual themselves, such as them moving their limb, for example to use a fork to eat. Passive function (also referred to as 'ease of care') is when a task is carried out by the individual using their unaffected (or less affected) limb or by someone else, such as a caregiver (or by a caregiver and the individual working together).
- ▶ Contractures are costly to the individual and to society. It is estimated that inpatient treatment and surgery for a single contracture currently costs about £18,000. Conservative approaches to preventing and managing contractures are needed, including splinting where appropriate.
- ▶ Occupational therapists and physiotherapists, as members of the wider health and social care team, play a key role in managing long-term neurological conditions. As part of a comprehensive, goal-directed rehabilitation or management programme, splinting can be a useful tool in preventing and correcting contractures.
- ▶ Functions, active or passive, both contribute towards the achievement of an individual's wider participation in society.
- ▶ Change and/or maintenance is required at the level of the body structure and function, in order to reverse, prevent or minimise the risk of contracture. ⁽⁴⁴⁾.
- ▶ Contractures, particularly of the hands, wrists and ankles, are common in individuals who have a neurological (brain) injury, such as cerebral palsy or stroke, or a progressive neurological condition. These can cause complications, such as:
 - pressure sores, for example where the fingernails 'dig in' to the palm
 - reduced ankle range, which may impact upon a person's ability to stand
 - reduced range at the hips, making the delivery of personal care very difficult
 - difficulty maintaining personal hygiene, for example of the palms if the hands and fingers are contracted, or delivering personal care if there is shortening of the adductor (inside thigh) muscles at the hip

It is extremely important to try to minimise the effects of these by appropriate positioning and splinting.

Prevention of contractures is, without doubt, the best approach

There is however, a lack of training about contractures for staff in social care. This results in a lack of understanding of the potential negative impacts of contractures, and a lack of confidence in managing residents who have, or are at risk of, a contracture ⁽⁴⁵⁾.

With training, the Contracture Risk Assessment Tool (CRAT) can be used to ascertain when refer to the GP for medical management, and when to request early intervention from appropriate Allied Health Professionals, (OTs or PTs), who can give advice on treatment and equipment (see Signposting Section on page 77).

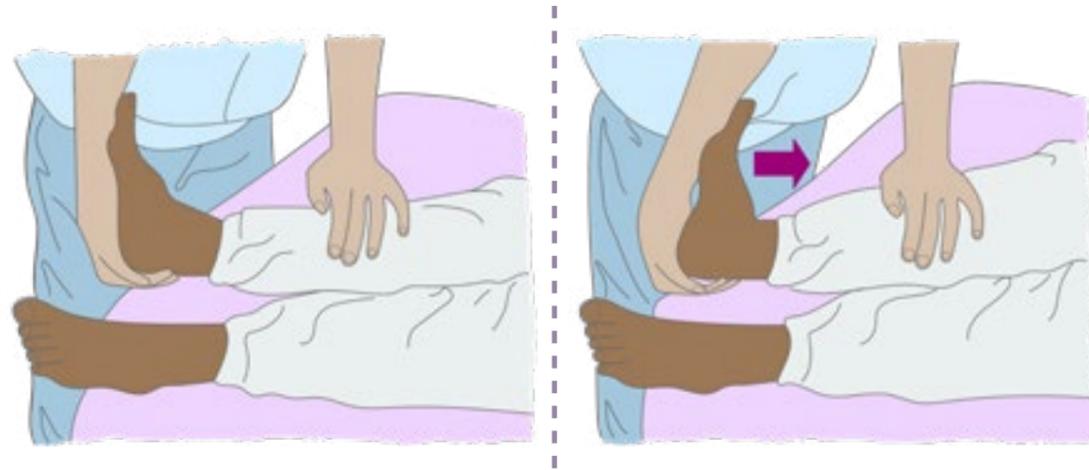
Splinting

- Defined as the process of applying a prolonged stretch through the application of a range of devices, most commonly a splint or a cast ⁽⁴⁴⁾.
- The most common areas of the body that need splinting are the wrists and ankles. Some people require splints for their elbows or knees, and others with spinal distortion may require a thoraco-lumbo-sacral-orthosis or (TLSO), otherwise known as a spinal brace.
 - Splinting is important for supporting an area of the body in the best possible position and thus helps to minimise contractures and muscle shortening. This in turn improves function and comfort.
 - An example of a splint is an ankle-foot orthotic (AFO), which is used to maintain the length of the calf muscles and the Achilles tendon (TA), which means a person maintains the ability to achieve a neutral ankle position, and therefore the ability to stand. Another example is a resting wrist splint to maintain the length of the wrist flexors (the muscles which bring the palm of the hand towards the inside of the forearm), thus preserving hand function. Splinting often reduces the need for surgery to release the tendons and it also reduces pain.
 - Splints are prescribed by specialist Physiotherapists and Occupational Therapists and it is imperative that all splinting regimes are followed, to reduce the risk of deterioration of joint range of movement.
 - It is also important to monitor splints regularly for complications. These may include pressure sores, pain, oedema (swelling), ischaemia (reduced blood supply) and nerve compression.



Activities/Personal Activities of Daily Living (ADLs and PADLS)

Passive Movements and Stretching Regimes:



This images show a passive calf stretch, which involves dorsiflexing the ankle (bending at the ankle to bring the foot up towards the shin).

Passive movements (PMs) and stretches are often used for people who are not able to move their limbs through the full range by themselves. Anyone who is required to spend a lot of time in a wheelchair or in bed, may benefit from passive movement and/or stretches exercises.

Evidence is insufficient to permit any firm conclusions about the effectiveness of PMs for joint mobility, spasticity or pain, among those with contractures or who are at risk of developing contractures, although PMs may have a small short-term effect on joint mobility, however, the grade level of evidence to support this claim is very low. Medium- and long-term effects of PMs on any outcome have not been investigated, including measures of activity limitations, participation restrictions or quality of life ⁽⁴⁶⁾. Importantly however, many individuals appear to experience benefits and most Therapists use and prescribe them. There may be many reasons for this, including the sensory benefits of being touched and moved, or repositioned, or simply the benefits of having meaningful engagement.

Possible benefits of passive movements

- Helping to maintain joint range of movement (ROM) and muscle length,
- Reducing tightness and pain, improving comfort and reducing stiffness
- Improving circulation
- Providing sensory stimulation, and therefore activity in weak muscles
- Providing relaxation and engagement

Teaching passive movements is beyond the scope of this resource as everyone is different, and it requires 'hands-on' practice to ensure the movements are carried out safely and effectively.

These exercises are prescribed by a qualified Physiotherapist, or in some cases by an Occupational Therapist, and it is important that caregivers are trained, usually by the prescribing Therapist, to:

1. Understand the importance of ensuring that the prescribed exercises are carried out
2. Have the confidence and skills to carry out the exercises correctly and effectively

For this reason, the prescribing Therapists will teach caregivers on a one-to-one basis, a programme that is specific to each individual who requires this type of intervention.

Background:

There has been a breadth of evidence since the late 1960's that supports the concept that the brain is able to 're-wire' its neural pathways through a process known as 'neuroplasticity' ⁽⁴⁷⁾.

Neuroplasticity refers to the capability of the nervous system to change. Nerve cells (neurons) have the capacity to change their structure and function, according to the response generated by activity and learning. This is the basis for memory and behavioural change arising from experience ^(48,49).

Plasticity takes place continuously, whether we are undertaking a task or doing absolutely nothing. Most importantly, plasticity can be positive (adaptive) or negative (maladaptive) ⁽⁵⁰⁾.

In day to day life this basically means: **if you don't use it, you lose it!**

The concept of neuroplasticity is particularly important in relation to ADLs and PADLs, where we have many opportunities to enable people to do more for themselves i.e. to be more independent, and thereby to achieve or maintain a sense of self-worth.

Movements involved in daily tasks promote positive changes to joint flexibility and allow muscles that are often in a shortened position to lengthen and stretch, as well as encouraging muscles to work more readily.

Any activity that involves moving, plays a key part in helping to improve independence and to increase confidence ⁽⁵¹⁾. If we encourage people to be more physically active in their ADLs and PADLs, for example if someone stands to get dressed instead of sitting to do it, they will make physical gains without feeling like they have had to participate in 'exercise'.

In practice:

It is tempting to do something *for* someone as, apart from seeming to be an act of kindness, it may appear to be quicker for you to do it, rather than to assist the individual to do it themselves. However, if, as the individual becomes more able, we gradually reduce the assistance we are giving to perform a task, they may be eventually able to do it independently.

We need to encourage individuals to be involved in their care physically, as well as simply being part of the decision making around their care, and, just as Principle 5 of the Mental Capacity Act emphasises a 'least restrictive' model, the same can be applied to ADLs (see 'more to less support' diagram on page 57).

Meaningful Activity

The value of 'occupation' and the worth of 'occupational' engagement needs to be understood here, if we are to make things meaningful to individuals⁽⁵²⁾. Occupation, in its broadest sense, includes paid or unpaid work, leisure, ADLs and sleep. The evidence shows a direct correlation between occupational balance and health and well-being, and that any imbalance in these areas can lead to a reduced sense of self-worth and purpose, which can impact upon levels of motivation, engagement and therefore activity. This means that we need to embody 'Person-Centred Care' by taking a truly whole person approach.

In order to engage a person, we need to find out what they need or want to do, and then we can incorporate this into an activity that is useful for them. For example, if a person is required to let the catering staff know their meal choice for the day, walking to the kitchen if they are mobile, (or at least part of the way), involves that individual in an occupational activity that means something to them, whilst simultaneously enabling them the opportunity of feeling they have contributed to what needs to be done, as well as increasing their activity levels.



Meaningful Objects

In a home care or care home environment, a person may not have access to all the objects that they once used⁽⁵¹⁾. They may then become unfamiliar with certain objects. We need to ensure we explore ways in which to refamiliarise individuals with objects that would ordinarily be used in their everyday lives, in order that they maintain the ability to use them⁽⁵³⁾.

Staff/Relative ADL/PADL Tips

*Just think how you would feel if you were able perform a task that you thought you had lost forever!
Also just think how you feel if you have helped someone to achieve their goal!*

1. Consider the following tasks:

- ▶ Dressing
- ▶ Hair brushing
- ▶ Teeth brushing
- ▶ Face washing
- ▶ Making a cup of tea/coffee

Are there certain tasks you automatically do for the individual you care for?

Do you think there is anything the individual may be able to do themselves, if you help them rather than doing it for them?

2. Consider brushing an individual's hair:

See the boxes below showing the options for most support to least support. Pick an individual whose hair you currently brush. Try the orange option first and if this is successful, gradually try the dark yellow, then light yellow, then the green option.

This may take several days, weeks, or even months. Remember improvements take time! It may take several times of doing this, but the person may 'reconnect' with the pattern and be able to do it on their own at some point. Remember, even if you only achieve the orange option, this is more empowering than the red option.

-  Brush the service user's hair for them
-  Assist the service to brush their hair, by placing the hairbrush in the individual's hand and then gently positioning your hand over their hand to perform the action of hair brushing with them.
-  Position the hairbrush in the service user's hand and give verbal prompts and encouragement for them to brush their own hair (give positive feedback where needed)
-  Position the hairbrush in front of the service user. Use prompts if needed. Be ready to carry out another task whilst the service user brushes their own hair. Keep an eye on the service user in case they need support.
-  Allow the service user to get their own hairbrush and to brush their own hair (with prompts if needed)

Other ADL/PADL Tasks

- Try other tasks too, such as face washing, teeth brushing, or changing the TV channel with the remote control
- Consider also all Moving and Assisting interventions. Ensure you always encourage the person to do as much as they can themselves
- Explain clearly, ahead of the task (demonstrating if necessary), what you are going to do, or what they are going to do
- Use enabling language – Try using short clear verbal cues such as, “brush”, rather than a long sentence
- Notice how you feel when the individual can do something more independently than before
- Notice how they feel
- Notice whether you have more time to do other things



Physical Activity

Background:

As well as poorer health and lower life expectancy, people with learning disabilities have lower levels of physical activity than their typically developing peers. Taking part in physical activity has been shown to have a number of benefits for both their physical health and psychological wellbeing⁽⁵²⁾. The latest statistics indicate that lack of physical activity is a major factor in the development of diabetes, high blood pressure, obesity, coronary heart disease, stroke and other conditions that effect the blood vessels. Physical inactivity is the fourth leading risk factor for global mortality, with the most recent figure sitting at 3.2 million deaths a year⁽⁵⁵⁾.

The Department of Health Physical Activity Guidelines, 2019, advocate that everyone should participate in daily physical activity to gain health benefits. Instead of including the maintenance of both good physical and mental health.

Light activities bring some health benefits compared to being sedentary, with more activity bringing greater improvements in physical function, as well as social benefits. The guidelines also state that there is some evidence that links an increase in physical activity to reduced feelings of social isolation and loneliness⁽⁵¹⁾.

Older adults particularly should include activities that improve strength, flexibility and balance, in order to maintain function and confidence, as well as to reduce the risk of falls⁽⁵¹⁾.

There is strong evidence that physical activity plays a vital role in our lives not just for the management and prevention of disease, but for the maintenance of independent living⁽⁵¹⁾, therefore physical activity is one of the fundamental elements of ‘Posture Friends’ and an Enabling Care Approach.





Daily Movement

With the average able-bodied person sitting around 12 hours per day, the Department of Health suggests that all adults should break up prolonged periods of being sedentary with light activity, when physically possible, at least with standing, as this has distinct health benefits ^(51,54).

We should be encouraging daily movement such as standing, in those who are able, and this should be followed up by promoting light activities. Beyond the areas of daily living (ADLs), this might include walking, cooking, dancing or arts & crafts, to name a few. These lower intensity, 'non-exercise' activities, such as standing, and walking, play a crucial role and account for more of our daily energy expenditure than moderate-to-high intensity activities ⁽⁵¹⁾.

In terms of encouraging daily movement, it helps to remember that **“some is good, more is better”** ⁽⁵¹⁾.

Standing Regimes:

For individuals who have been assessed by a specialist Physiotherapist or Occupational Therapist as able to stand with equipment* (such as a standing frame), it is extremely important that the prescribed standing regime is in the care plan and is carried out.

*The benefits of standing almost always outweigh the risks of not standing** (56)*

Benefits of standing ⁽⁵⁷⁾:

- Improved bone density
- Improved muscle strength
- Improved gastrointestinal function
- Improved bowel and bladder function
- Improved respiratory function
- Improved social interaction
- Improved balance and coordination
- Increased wellbeing
- Increased participation



It is important to assess the person's capacity to make decisions about activities like standing, each time the activity is carried out and to gain the person's consent if they have capacity to make this decision. If the person lacks capacity to agree to this activity, it should be carried out in the person's Best Interests, providing the benefits of standing outweigh any risk of physical or emotional harm to the person. This must initially be assessed by the prescribing Therapist, but for a person with fluctuating capacity, it will need to be assessed on a task-to-task basis***.

A risk assessment must be carried out and followed. This must include:

- Preparation and checking of the area and equipment
- Safety considerations, for example, unpredictable behaviour
- Number of staff required
- Equipment that is necessary and how it should be used
- Application of any appropriate splints e.g. ankle-foot-orthoses (AFOs), or spinal brace
- The best way to communicate with the individual, using enabling language****
- Consideration of current ability (e.g. are they recovering from an illness)
- Safety considerations once the person is standing
- Ensuring any catheter bags are not in need of emptying

**See the Equipment section of this resource on page 46*

***See the Physical Activity section of this resource for more information on the importance of standing regimes on page 59*

****See the Mental Capacity section of this resource on page 18*

*****See the Communication section of this resource on page 20*

If there are any concerns or difficulties with a prescribed programme or piece of equipment, the prescribing Therapist **MUST** be contacted for advice.
Difficulties may include:

- A lack of staff knowledge or confidence in using the equipment
- A lack of willingness or resistance from the person to participate in the activity
- A lack of physical ability of staff to safely achieve the activity
- A lack of physical ability of the individual to safely achieve the activity
- A change in physical or mental ability that impacts upon the task being carried out successfully



Opportunities for Physical Activity

"If physical activity were a drug, we would refer to it as a miracle cure, due to the great many illness it can prevent and help treat."

UK Chief Medical Officers, (2019)



Physical Activity - Activities of Daily Living

Given that “some movement is better than none”, as the CMO guidelines state, encouraging participation in personal care tasks, such as face washing, hair brushing, teeth brushing, and dressing is vital in helping someone who is sedentary for most of the day, to increase their level of physical activity⁽⁵⁸⁾.

Sit-To-Stand

Break up periods of sedentary behaviour by practising standing every hour*. This uses most major muscle groups, helps reduce the risk of pressure sores, and promotes healthy bone strength through weight bearing. It helps relieve stiffness and increases confidence. It also helps to maintain the function of all the body systems including the respiratory, circulatory, digestive and nervous systems^(59, 60).

Mobility Practice

For those who are mobile, increasing distance walked, and/or frequency of walking practice, as well as practising stair climbing, will increase levels of physical activity*⁽⁶¹⁾.

Enabling Tasks

Encourage simple everyday tasks and hobbies, such as tidying around the house, gardening, getting a cup of tea or coffee, cooking, walking in the park, doing arts & crafts, playing games and creating music^(62, 58).

See HCPA's Enabling Care Approach Resource for additional tips

Case Study



Lisa - 55

Lisa is living with a mild learning disability Multiple Sclerosis and has not had any falls in the last year. She has good days and bad days; there are times where she is unable to move her legs, but other times, she can transfer from her wheelchair confidently.

Occasionally frustrated, Lisa set a personal goal to become more independent, even on her bad days. Her actions included breaking up time spent sitting by practising the movements that make up sit-to-stand, such as lifting her bottom off the chair.

By incorporating this into her daily routine, the care staff have commented on how she needs far less assistance to do sit-to-stand transfers. This has significantly decreased Lisa's dependence. With this newly rediscovered independence, she is continuing to work with the staff, friends and family to be able to re-learn other tasks.

**Always ensure the Care Plan, Risk Assessments and safe Moving and Assisting Practices are followed, and that they are reviewed and updated accordingly*

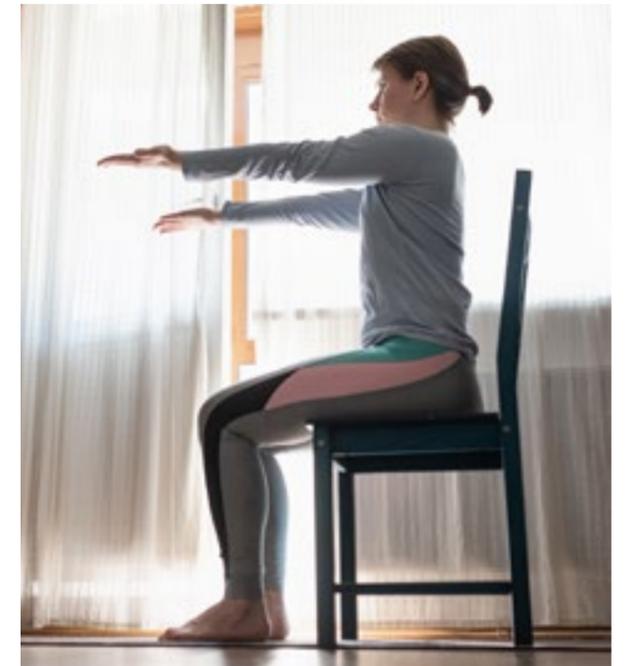
Chair-Based Exercise:

These classes can be delivered to specific groups

Exercise refers to planned physical activity, which is one way to meet government practice, that everyone “should aim to accumulate at least 150 minutes of moderate intensity aerobic activity per week, building up gradually from current levels”.

Chair-Based Exercise is a great way for people who are unable to exercise in standing, to gradually build up their activity levels, with evidence suggesting it boosts physical function, independence and mental wellbeing.

Having planned time for physical activity, such as Chair-Based Exercise also contributes to a sense of control over, and responsibility for, one's own health and wellbeing⁽⁶³⁾.



OTAGO:

These classes can be delivered to specific groups

It is important to highlight that a loss of muscle strength in advancing age, is the primary limiting factor for functional independence, and that it is this loss that we need to address with an Enabling Care Approach⁽⁵⁴⁾.

Additionally, it needs to be understood that “good balance and mobility are essential to the successful performance of most activities of daily living”⁽⁵⁶⁾. Therefore, in accordance with best practice, adults who are at risk of falls, should, as much as possible, be supported to undertake physical activities that address both strength and balance.

OTAGO is a specific programme of physical exercises that will challenge both balance and strength, and which has shown improvements in these areas, in individuals who have participated in the programme⁽⁶³⁾.

Staff Tips:

Think about what simple things the individuals you care for could do to increase their physical activity levels.

Try and before:

- Practising 'sit to stand' (with your supervision if needed) at intervals throughout the day
- Set 'mini goals' to walk slightly further each day
- Follow the exercises in the HCPA StopFalls Brochure

Consider undertaking HCPA training to become a Chair-Based Exercise/OTAGO Instructor.

**Ensure appropriate risk assessments are carried out*

Physical Activity - Risks, Barriers and Considerations

There is enough evidence to categorically state that the benefits associated with physical activity outweigh the risks of not being active (51). Fear of injury, or of making an existing condition worse, can often be a barrier to undertaking physical activity, but there is little evidence to suggest that physical activity is harmful if it is carried out at an intensity and in a manner appropriate to the individual's current level of ability. Starting at a low intensity, and gradually building up the frequency, intensity or duration of the physical activity, is the safest way for an individual to progress. Seeking advice from a trained professional, such as a GP or Physiotherapist, is of utmost importance if there are any doubts about an individual's health or safety when they are participating in physical activity⁽⁶⁴⁾.

Specific Groups

Older adults with frailty, moderate to severe dementia, a history of vertebral fractures or regular falls, may initially require any new exercise to be prescribed and supervised by a trained professional, to ensure that the exercises are appropriate and safe, and that they do not cause injury. Additionally, people with Chronic Fatigue Syndrome (CFS/ME), otherwise known as myalgic encephalomyelitis (ME), may need to carefully moderate how much activity they undertake during 'flare-ups' of their illness. See page 68 for more details.

Adults with a Physical Disability: It is a myth that physical activity is harmful for individuals with disabilities. It is, however, important that any activity is agreed, safe and appropriate to the individual.



Specific Conditions

Osteoporosis means 'porous bone' and occurs when the body loses more bone than it is naturally replacing. Bones become weak/'brittle' and fracture (break) easily as a result.

Osteopenia is the stage at which someone has a lower bone density than average for their age, but it has not yet progressed to the point of osteoporosis.

Losing bone is a normal part of ageing, but sometimes the loss is faster than normal. Women are at more risk than men, and they lose bone rapidly in the first few years after menopause, particularly if their menopause begins before age 45, or if they have had their ovaries removed. There are several factors which increase the risk of developing osteoporosis: a family history of osteoporosis; taking high doses of steroid medications for more than three months; other medical conditions such as: inflammatory conditions, hormone-related conditions or malabsorption problems, long-term use of medications that affect bone strength (such as anti-convulsant medication for the treatment of epilepsy, or anti-oestrogen tablets for the treatment of breast cancer), eating disorders and low calcium and vitamin D intake, low body mass index (BMI), heavy drinking or smoking, and a lack of regular physical activity. For a person who does not weight bear (i.e., someone who does not stand or walk) and/or who is taking anti-epileptic medication, such as a person with PMLD, the risk of osteoporosis is extremely high. In addition, a person who is prone to chest infections (i.e., someone who is not mobile, or someone with Chronic Obstructive Pulmonary Disease (COPD)), may take steroid medications, which increases the likelihood of osteoporosis.

Tips for individuals with osteoporosis and osteopenia

- **Vitamin D** – People with a learning disability are almost twice as likely to be deficient in Vitamin D than the general population⁽⁶⁵⁾. Vitamin D helps the body absorb calcium and phosphorous from the food we eat and therefore it is important for bone health. You get most of the Vitamin D you need from sunlight. You only need to go outside for 20 minutes a day between April and September. Ensure that during the winter months (October-March) everybody takes a Vitamin D supplement in the dose of 10µg per day; This does not need to be prescribed and can be purchased from supermarkets or pharmacies in the form of tablets, sprays, gummies or liquids. During the summer months, most people should be able to make their own Vitamin D through short periods of sun exposure. However, for the most vulnerable client groups, taking Vitamin D in the dose of 10µg per day all year round is beneficial⁽⁶⁶⁾
- **New weight bearing activities** – Ensure that a medical review is carried out before any new weight bearing activity is undertaken by a person who has not been up on their feet for some time. This includes a person who has not been weightbearing as they usually would, for example because they have been unwell
- **Gentle handling** - This is extremely important to minimise the risk of potential fractures, for example of the ribs
- **Falls** - Ensure there is careful consideration about any physical activity that involves a risk of falls Provide a safe environment that has plenty of support options available, including enough staff to hand, and which is free of trip hazards, such as carpets, wires, and obstacles. Refer to a specialist Physiotherapist for balance exercises, if appropriate for the individual or consider a Postural Stability Class*

*see HCPA's StopFalls website: <https://www.hcpastopfalls.info> for more details

Specific Conditions (cont.)

Chronic obstructive pulmonary disease (COPD): This is the name for a group of lung conditions that cause breathing difficulties. It includes emphysema (damage to the air sacs in the lungs) and chronic bronchitis (long-term inflammation of the airways). COPD is a common condition that mainly affects middle-aged or older adults who smoke. Many people do not realise they have it. The breathing problems tend to get gradually worse over time and can limit a person's normal activities, although treatment and pulmonary rehabilitation (a specialised programme of exercise and education) can help keep the condition under control⁽⁶⁷⁾.

CFS/ME: A debilitating, long-term illness with a wide range of symptoms. The most common symptom is extreme tiredness. Exercising usually makes the symptoms of CFS/ME worse. Sometimes the effect is delayed and the person feels very tired a few hours after they have exercised, or even the next day. Graded exercise therapy (GET) is a structured exercise programme that aims to gradually increase how long a person can carry out a physical activity. It usually involves exercise that raises the heart rate, such as swimming or walking, and is adapted to the person's physical capabilities by a trained specialist with experience of treating CFS/ME. If possible, this should be offered on a one-to-one basis⁽⁶⁸⁾.

Postural Hypotension (particularly in individuals where this is already diagnosed): This causes a drop in blood pressure, which results in dizziness (and potentially fainting) on moving from a sitting to a standing position. See tips on page 26.

Hip or other lower limb joint replacements: Movement may be painful or restricted. With some hip replacements there is a risk of dislocation. For example, if the individual sits on a low chair (that puts the angle at the hip at less than 90 degrees) or if they cross their legs. This should be documented in their post-operative instructions. Advice should be sought from a qualified Physiotherapist if there is ANY uncertainty regarding the inclusion/exclusion criteria for certain exercises.

Osteoarthritis: Painful, swollen joints are the main symptoms associated with osteoarthritis. Whilst exercise is thought by many to reduce these symptoms, it is important that:

1. the type of exercise and the intensity of the activity is suitable for the individual
2. the joints are in good alignment (not twisted) wherever possible, so that the symptoms are not exacerbated. Including a gentle warm-up before more intense exercise can help to minimise pain, as it helps to improve circulation, and reduce the stiffness that is often felt as a result of prolonged inactivity. Appropriate timing of medication can also be extremely helpful. Seek advice from a qualified Physiotherapist if there is uncertainty regarding inclusion/exclusion of a certain exercise.

The following general tips may also help when considering physical activity:

- Consider the specific conditions that a person may have. Look up conditions. Ask questions, and discuss issues with health professionals (such as GPs, Physiotherapists, Occupational Therapists and Specialist Nurses) to expand your knowledge
- Always ensure appropriate referrals are made to a qualified Allied Health Professional (a Physiotherapist), for prescription of exercises where necessary
- Monitor the individual for signs of pain, adverse effects, or deterioration, and stop/report/refer accordingly
- Ensure pain relief medication is timed appropriately
- Ensure, as far as possible, that the individual's joints are in good alignment when participating in an exercise*
- Ensure risk assessments are in place, and that they are followed and regularly reviewed
- Ensure that the Mental Capacity Code of Practice⁽⁶⁹⁾ is followed and that:
 - ▶ Appropriate information is given to individuals for them to make an informed choice where possible
 - ▶ Capacity to make decisions about physical activity is assessed and documented
 - ▶ Where the individual lacks capacity to make decisions about their physical activities, Best Interest Decisions (including strategies that are known to positively engage the individual) are agreed, documented, and followed
- When practising standing, be aware of potential **Postural Hypotension**, (particularly in individuals where this is already diagnosed). It is extremely important to:
 - ▶ Check, on standing, that the individual is steady and ready to continue
 - ▶ Encourage marching on the spot to improve blood flow back up to the brain
 - ▶ Avoid moving forwards if in ANY doubt
 - ▶ Ensure a risk assessment is in place and that it is followed. For an individual who tends to start to step forwards before they are 'steady', this may include three members of staff, one who needs to be ready with a wheelchair behind

*Refer to HCPA's Enabling Care Approach – Posture and Positioning Module for more details

Engaging a person with a cognitive impairment

Just because someone is living with, for example, a learning disability and/or dementia, it does not mean they cannot engage in exercise. Try the following tips below on how to engage someone living with a cognitive impairment:

- ✓ Give clear instructions
- ✓ Use verbal and non-verbal instructions
- ✓ Use eye contact appropriately
- ✓ Try using music that the person likes
- ✓ Use fun games within the session to maintain high levels of engagement including, ball, sensory and reminiscence games

Social Engagement

People with a learning disability should be supported to have the same choice and control over their lives as others. This includes being supported to develop and maintain community links and opportunities that enable them to engage in everyday activities, such as education, employment, housing, and transport and leisure services. Whilst it is important to understand duty of care in relation to risk-taking, the focus should always be on a person's right to take positive risks, so they can engage in meaningful occupations and activities. It is important for people with a learning disability to be active in daily life as it affects their health, wellbeing, and quality of life, as well as that of their communities ⁽⁷⁰⁾.

It stands to reason that if individuals feel they are more independent and able to contribute to society, they will feel more valued.

Caregiver tips

- Identify people who are at the most risk of a decline in their independence
- Provide opportunities for people to get involved with
- Look at putting a plan in place to help overcome barriers. Establish the kinds of support a person may need for tasks such as, travelling, communicating, making decisions and using services
- Have meaningful conversations to find out what may help someone continue to develop their interests, social life and community involvement
- Source support from local services and organisations
- Identify ways to get people involved in social activities, and educational or occupational opportunities



Goal Setting

SMART Goals:

should be:

Specific

Goals need to be as clear and as concise as possible so that they can be easily understood by everyone. A goal might look something like this: Janet wants to be able to stand unassisted for 30 seconds. The standing unsupported is the specific part of the goal.

Measurable

Targets need to have clear indicators, that allow progress and achievement to be tracked. In this example, we know we can use time as our measurement to record how long Janet stands for.

Achievable

A goal needs to be realistic and attainable in order for the person to have a chance of success. It needs to be just beyond the boundaries of the person's abilities, but not too far so as to discourage them. This current goal is good because Janet can currently stand unassisted for 10 seconds.

Relevant

This ensures that the goal matters to the person; a question you might ask them is: "Is this a step towards what you want to achieve?". This goal is relevant because if Janet can stand unassisted for 30 seconds, she will be able to pull up her trousers independently after using the toilet, and this is meaningful to her.

Timed

Having a meaningful time frame is essential motivation for working towards a goal. A deadline can also increase commitment and focus, whilst giving a measurable end date by which the goal will be achieved.

It may be appropriate to use Goal Attainment Scale (GAS) Goals or the Patient Specific Functional Scale (PSFS), as well as other commonly used outcome measures – these are taught on Tier 3 of the 'Posture Friends' training.

Please contact the HCPA Team for more details

Signs of Deterioration and Signposting

Background of acute illness:

The 2018 LeDeR annual report⁽³⁾ found that chest infections, pneumonia, aspiration pneumonia, and sepsis were the main causes of death. Mortality reviews also found that constipation, failure to recognise physical deterioration, and the inappropriate application of the Mental Capacity Act to physical health issues, were also significant factors in avoidable deaths⁽³⁾.

Other common causes of acute illness in a person with a learning disability are urinary tract infections (UTIs), exacerbations of asthma, acute gastrointestinal problems, abnormal blood sugar levels, epileptic seizures and extremely high blood pressure, or any other infection.

Sepsis is a life-threatening reaction that can result from any infection. It happens when the immune system overreacts to an infection and starts to damage the body's own tissues and organs. Sepsis is sometimes called septicaemia or blood poisoning⁽⁷¹⁾.

A person with a learning disability may be unable to communicate that they are feeling unwell. Additionally, they are likely to be at a higher risk of infection (and therefore sepsis) and may deteriorate more quickly than a person who does not have a learning disability.

The LeDeR findings highlight the need for an improved level of caregiver awareness of the risk factors, signs, consequences and management of these acute illnesses in people with a learning disability⁽¹⁸⁾. The focus should be on PREVENTION.

Keeping people active, healthy and independent is one of the main aims of an Enabling Care Approach and one of the most important ways in which we can 'enable' people to remain well, is through early detection of acute deterioration. This may avoid unnecessary hospital admissions and potential deaths, and in turn will help reduce the strain on an already overburdened NHS⁽⁷²⁾.

Factors that cause difficulty taking deep breaths, or that cause swallowing difficulties (dysphagia), increase the risk of a person with a learning disability getting a chest infection. These include:

- Body distortion
- Immobility
- The added onset of a degenerative neurological injury, such as dementia
- Onset of a neurological injury, such as a stroke
- Any other condition which results in immobility, or in difficulty moving

If a person has dysphagia, poor oral health is a significant risk factor for aspiration pneumonia, due to the increased possibility of bacteria from the mouth entering the respiratory tract.

The 'Top to Toe Handbook', 2019⁽⁷³⁾, is a comprehensive guide to supporting the early recognition of ill health in people with a learning disability, and includes information about most of the conditions mentioned here. The DisDAT (mentioned on page 21) can be helpful in recognising signs of illness in a person who has difficulty communicating.

This 'Posture Friends' resource booklet focusses on the Basic Health Observations that can be used to assess and manage an acutely unwell person. The tool that is becoming widely used in community settings is RESTORE2* (Recognise Early Soft Signs, Take Observations, Respond, Escalate 2), and includes the NEWS2* (National Early Warning Score 2), which involves an easy to follow evaluation of clinical observations and appropriate clinical responses⁽⁷⁴⁾. The clinical observations are respiration rate (RR), oxygen saturations (SpO2), temperature, systolic blood pressure (BP), heart rate (HR), level of consciousness/confusion. The RESTORE2 and NEWS2 tools promote a standardised response to the assessment and management of acutely unwell individuals. The inclusion of the SBARD (Situation, Background, Assessment, Recommendation, Decision) communication tool supports earlier identification of deterioration and access to treatment, through improved communication between caregivers and healthcare staff, as well as between community and acute settings⁽³⁾.

The RESTORE2mini* is a version of the RESTORE2, which does not include the NEWS2 section.

These tools are not a replacement for clinical judgement and should always be used with reference to the individual's care plan.

Lastly, it is vital that, if deaths from sepsis are to be prevented, caregivers need to be made aware of the fact that: Sepsis is a time critical condition, and immediate action is required. The Community Carers Sepsis Screening and Action Tool, which has been developed by the UK Sepsis Trust, is an extremely useful tool, which provides a clear flowchart for the early detection and management of sepsis*.

**These are available on the HCPA online resource library: <https://www.hcpastopfalls.info/resource-library/>*

In Practice: The practice of taking vital signs has not traditionally been embraced in many non-Nurse led care settings. Recently however, there is a drive towards reducing inappropriate ambulance call-outs and unnecessary hospital admissions.

Over 60% of patients admitted to hospital as an emergency have a long-term health condition⁽⁶⁰⁾. Nearly a quarter were seen to be at the lowest level in managing their health⁽⁶⁰⁾. Those who were able to manage their health conditions had 38% fewer emergency admissions and 32% fewer attendances to A&E⁽⁶⁰⁾.

Spotting signs of an acutely unwell person (acute deterioration)

- Think about physical observations – you may get a ‘hunch’ that someone “just doesn’t seem themselves”, or is a little “off colour” Use RESTORE2 or RESTORE2mini
- What can you see, hear, smell or feel on the service user? – these things may have contributed to your hunch. For example, you may have smelt an odour which you think could be a chest infection (CI) or a urinary tract infection (UTI). Notice these observations and report them, document them, and monitor/refer the service user appropriately
- Have an understanding of vital signs - temperature, heart rate (HR), respiratory rate (RR), blood pressure (BP) and oxygen saturations (SPO2). Refer to HCPA’s Posture Friends Tier 2 Respiratory Module or other HCPA Basic Health Observations Training NEWS2
- Check these values against the individual’s baseline measurements. Their ‘Chest Passport’, should contain this information

VITAL SIGNS	NORMAL RANGE	HOW USUALLY MEASURED IN THE CARE SETTING
Temperature	36.5°C to 37.3°C; (average 37°C)	Non-contact infrared thermometer
Heart Rate (pulse)	60 to 80 beats per minute	<ul style="list-style-type: none"> ■ Manually at the wrist (radial pulse) using a minute timer ■ Using a Heart Rate monitor e.g. one on a Pulse Oximeter
Respiratory Rate	12 - 18 breaths per minute at rest	<ul style="list-style-type: none"> ■ Manually by counting chest movement (in and out =1)
Blood Pressure	90/60 mm Hg to 120/80 mm Hg.	<ul style="list-style-type: none"> ■ Automatic blood pressure monitor ■ Manually (by a Nurse) with a sphygmomanometer
Oxygen Saturations	94-100%*	<ul style="list-style-type: none"> ■ Pulse Oximeter (finger/toe/ear) ■ Arterial Blood Gases (ABGs) – only likely in hospital or by Community Respiratory Team

⁽⁷⁵⁾ Values taken from: www.england.nhs.uk, accessed 11.8.20, The Atlas of Shared Learning, Case study. Introducing bedside vital signs devices at Imperial College Healthcare NHS Trust4, March 2019. Leading Change, Adding Value Team (Nursing, midwifery and care).

* In a person who has Chronic Obstructive Pulmonary Disease (COPD), who is known to retain Carbon Dioxide (CO₂), a normal range for them may be 88-92%

- Consider obtaining the WHZAN Blue Box’

Whzan automatically calculates the Royal College of Physicians’ National Early Warning Score (NEWS2), which is part of the RESTORE2 assessment tool, and is in use throughout the UK supporting the analysis of illness, nutrition, hydration, frailty and other conditions ⁽⁷⁶⁾. It includes health and activity pattern recognition, and independent NHS case studies demonstrate that Whzan telehealth achieves substantial savings in resources, improves patient lives and empowers care workers.

Contact: <https://www.whzan.uk/care-homes> or contact HCPA for further details

Background of Chronic illness:

People with a learning disability often have poorer long term physical and mental health than other people, and are at increased risk of vulnerabilities relating to unquantified changes to health due to growing older. This does not need to be the case. Annual health checks are available for adults and young people aged 14 or, over with a learning disability. It is extremely important that individuals with a learning disability are supported to attend their annual health check.

Many factors can affect the health and well being of individuals with a learning disability. They may experience physical deterioration, due to; e.g. the progression or non-optimal management of disease; following acute illness or injury; or because of the ageing process

They may also experience mental health or emotional deterioration, due to; e.g. the progression or non-optimal management of disease; following acute emotional upset or depression; or because of the ageing process.

Physical and Mental Health are inextricably linked, so can have a profound effect on each other, and consequently on the overall functioning and well-being of the individual.

Additionally, the effects of certain medications can have adverse effects on individuals, both in the short and the long term (see table on page 76 for common side effects).

Polypharmacy (more than four different medications) is widely accepted as a factor in the risk of falls (Please refer to HCPA’s StopFalls resources for further information).

**Please see HCPA’s Resource Library for RESTORE2 and NEWS2 forms*

Spotting Signs of Chronic Deterioration

Recognition of the signs of more chronic problems, can also delay or even prevent further deterioration, especially when accompanied by timely signposting to the appropriate Health Professional ⁽⁷³⁾.

These include:

- Worsening postural alignment
- Worsening mobility
- Increased spasms
- Behavioural changes (e.g. agitation or sleep changes)
- Increased anxiety or depression
- Appetite or weight changes
- Changes in skin integrity
- Worsening pain or discomfort
- Increased UTIs or bowel problems

REMEMBER! YOU can help reduce deterioration by acting early and referring to the appropriate Health Professional

TIPS

- **Know the individual you care for!**
- Be observant with regards changes in individuals
- Don't assume that deterioration is inevitable
- Question whether something (or someone) may help someone to improve
- Keep up to date with training that includes enablement skills, postural alignment, information on specific conditions, particularly neurological and respiratory conditions
- Ensure your approach is supportive and understanding
- Use understanding and compassion
- Listen, encourage and guide where needed
- Communicate clearly in the most effective way for your specific individuals
- Try to be patient and calm. Practise relaxation and mindfulness techniques yourself!
- Consider which extra care plans and Risk Assessments might need to be included for a service-user with e.g. a neurological condition that causes them to have increased tone in their legs?
- Be curious and be confident to ask questions about a individual potential needs
- Consider what other members of the in-house Multidisciplinary Team (MDT) might you need to liaise with?
- Consider what members of the wider MDT might you need to involve?
- Consider a person's values and beliefs regarding their health. A person's health and wellbeing needs are likely to be better met if their needs are identified and their goals are agreed together, and if they are given greater choice and control over the care and support they receive ⁽⁷⁷⁾.

In Practice:

The practice of taking vital signs has not traditionally been embraced in many non-Nurse led care settings. Recently however, there is a drive towards reducing inappropriate ambulance call-outs and unnecessary hospital admissions.

- Over 60% of patients admitted to hospital as an emergency have a long-term health condition ⁽⁷²⁾
- Nearly a quarter were seen to be at the lowest level in managing their health. ⁽⁶⁰⁾
- Those who were able to manage their health conditions had 38% fewer emergency admissions and 32% fewer attendances to A&E. ⁽⁷²⁾

Signposting to Members of the Wider MDT

Use this guide when considering who is the best Allied Health Professional (AHP) for the needs of the individual in your care. Where possible, use accepted assessment tools, such as DisDat for signs of distress, the FRAT for risk of falls, the CRAT for risk of contractures, or other measurements, such as the Waterlow Score and weight etc.

PROBLEM	ALLIED HEALTH PROFESSIONAL (AHP) TO REFER TO*
WORSENING MOBILITY, DIFFICULTY USING MOBILITY AID, MOBILITY AID INAPPROPRIATE OR WRONG SIZE/HEIGHT	PHYSIOTHERAPIST / OCCUPATIONAL THERAPIST
POSTURAL PROBLEMS PROBLEMS WITH SEATING OR POSITIONING IN BED	PHYSIOTHERAPIST OCCUPATIONAL THERAPIST, WHEELCHAIR SERVICES
INCREASED MUSCLE TONE (CAUSING SPASMS STIFFNESS/PRESSURE AREAS DEVELOPING/POSTURAL PROBLEMS)	PHYSIOTHERAPIST (for positioning advice) GP/NEUROLOGY CONSULTANT (for medication review) SPECIALIST TEAM (e.g. Parkinsons Nurse, MS nurse) OCCUPATIONAL THERAPIST/ PHYSIOTHERAPIST specialist orthotist (for splints) TISSUE VIABILITY NURSE (for pressure areas) DIETICIAN (for nutritional review)
NOT MANAGING/COUGHING ON FOOD OR FLUIDS	SPEECH & LANGUAGE THERAPIST (SALT)
BOWEL OR BLADDER DYSFUNCTION	BOWEL HEALTH SERVICE CONTINENCE NURSE DISTRICT NURSE
RECURRENT INFECTIONS E.G. CHEST, UTI	NURSE SPEECH AND LANGUAGE THERAPIST (for chest infections) PHYSIOTHERAPIST (for chest infections), DENTIST (for chest infections) COMMUNITY RESPIRATORY TEAM (for COPD or someone on oxygen)
WORSENING COMMUNICATION	SPEECH AND LANGUAGE THERAPIST
WEIGHT LOSS OR WEIGHT GAIN	DIETICIAN OR SALT
BEHAVIOURAL/COGNITIVE CHANGES	OCCUPATIONAL THERAPIST CLINICAL PSYCHOLOGIST NEUROPSYCHOLOGIST
EMOTIONAL CHANGES	PSYCHIATRIST (medication) TALKING THERAPIST (counselling, Cognitive Behavioural Therapy CBT) Holistic Therapist

**Please note the list of Health Professionals here is not exhaustive, and the referral pathway you need to use, as well as the team you need to access, may differ for differently commissioned services. Contact HCPA if you have identified the professional help you think you need, but are unsure of the most appropriate referral pathway.*

Medicines and Falls Risk

This list is to raise awareness of the most commonly prescribed drugs that can contribute to falls risk. The grading of the drugs has been adapted from; Medicines and Falls in Hospital: Guidance by John Radcliffe Hospital, Oxford, March 2011 and is approved by the British Geriatrics Society.

High risk Can commonly cause falls alone or in combination			Moderate risk Can cause falls, especially in combination			Lower risk Possibly causes falls, particularly in combination		
Drug Name	Common Use	Effects on Falls Risk						
Alfluzosin	Benign prostatic hyperplasia	Drop in blood pressure on standing						
Amitriptyline	Depression	Drop in blood pressure on standing, drowsiness, slow reactions, impaired balance						
Amlodipine	Hypertension, Angina	Low blood pressure, drop in blood pressure on standing						
Atenolol	Hypertension, Angina, Arrhythmia	Low blood pressure, drop in blood pressure on standing, slow heart rate						
Baclofen	Severe spasticity of voluntary muscle	Sleepiness and reduced muscle tone						
Bendroflumethiazide	Oedema, Hypertension	Low blood pressure, drop in blood pressure on standing and sleepiness						
Betahistine	Vertigo, Tinnitus	Sleepiness						
Bisoprolol	Hypertension, Angina, Heart failure	Low blood pressure, drop in blood pressure on standing, slow heart rate						
Bumetanide	Oedema	Low blood pressure, drop in blood pressure on standing						
Candesartan	Hypertension, Heart failure	Low blood pressure						
Captopril	Hypertension, Heart failure	Low blood pressure, drop in blood pressure on standing						
Carbamazepine	Epilepsy	Sleepiness, slow reactions, unsteadiness and lack of movement control						
Carvedilol	Hypertension, Angina, Heart failure	Low blood pressure, drop in blood pressure on standing, slow heart rate						
Chlordiazepoxide	Anxiety, Acute alcohol withdrawal	Drowsiness, slow reactions, impaired balance						
Chlorphenamine	Allergy, Urticaria	Drowsiness and blurred vision						
Chlorpromazine	Psychosis	Drop in blood pressure on standing, sleepiness, slow reflexes, loss of balance						
Chlorthalidone	Oedema, Hypertension, Heart failure	Low blood pressure, drop in blood pressure on standing and sleepiness						
Cinnarazine	Nausea, Vomiting, Vertigo, Tinnitus	Sleepiness						
Citalopram	Depression	Drop in blood pressure on standing, confusion						
Clomipramine	Depression, Phobia	Drop in blood pressure on standing, drowsiness, slow reactions, impaired balance						
Clonazepam	Epilepsy	Drowsiness, slow reactions, impaired balance						
Codeine	Pain	Sleepiness, slow reactions, impaired balance, delirium						
Dantrolene	Severe spasticity of voluntary muscle	Sleepiness, reduced muscle tone						
Diazepam	Insomnia, Anxiety	Drowsiness, slow reactions, impaired balance						
Digoxin	Heart Failure	Slow heart rate						
Diltiazem	Hypertension, Angina	Low blood pressure, drop in blood pressure on standing						
Donepezil	Dementia	Fainting						
Dosulepin	Depression	Drop in blood pressure on standing, drowsiness, slow reactions, impaired balance						
Doxazosin	Hypertension	Low blood pressure, drop in blood pressure on standing						
Doxepin	Depression, Pruritus in eczema							
Duloxetine	Depression, Anxiety	Drop in blood pressure on standing, sleepiness, dizziness, confusion						
Enalapril	Hypertension, Heart failure	Low blood pressure, drop in blood pressure on standing						
Felodipine	Hypertension, Angina	Low blood pressure, drop in blood pressure on standing						
Fluoxetine	Depression	Confusion						
Fluphenazine	Psychosis	Drop in blood pressure on standing, sleepiness, slow reflexes, loss of balance						
Flurazepam	Insomnia	Drowsiness, slow reactions, impaired balance						
Furosemide	Oedema, Hypertension	Low blood pressure, drop in blood pressure on standing						
Gabapentin	Chronic pain	Drop in blood pressure on standing, sleepiness, unsteadiness						
Galantamine	Dementia	Fainting						
Glycerol trinitrate (GTN)	Angina	Drop in blood pressure on standing						
Haloperidol	Psychosis	Drop in blood pressure on standing, sleepiness, slow reflexes, loss of balance						
Hydroxyzine	Pruritus	Drowsiness and blurred vision						
Irbesartan	Hypertension	Low blood pressure						

Drug Name	Common Use	Effects on Falls Risk
Isosorbide mononitrate	Angina	Drop in blood pressure on standing
Lercanidipine	Hypertension	Low blood pressure, drop in blood pressure on standing
Lisinopril	Hypertension, Heart failure	Low blood pressure, drop in blood pressure on standing
Lorazepam	Insomnia, Anxiety	Drowsiness, slow reactions, impaired balance
Lortemazepam	Insomnia	Drowsiness, slow reactions, impaired balance
Losartan	Hypertension, Heart failure	Low blood pressure
Metolazone	Oedema, Hypertension	Low blood pressure, drop in blood pressure on standing and sleepiness
Metoprolol	Hypertension, Angina, Arrhythmia	Low blood pressure, drop in blood pressure on standing, slow heart rate
Mirtazapine	Depression	Drop in blood pressure on standing, drowsiness, slow reactions, impaired balance
Morphine	Pain	Sleepiness, slow reactions, impaired balance, delirium
Moxonidine	Hypertension	Low blood pressure, drop in blood pressure on standing and sleepiness
Nicorandil	Angina	Drop in blood pressure on standing
Nifedipine	Hypertension, Angina	Low blood pressure, drop in blood pressure on standing
Nitrazepam	Insomnia	Drowsiness, slow reactions, impaired balance
Nortriptyline	Depression, Neuropathic pain	Drop in blood pressure on standing, drowsiness, slow reactions, impaired balance
Olanzapine	Psychosis, Agitation	Drop in blood pressure on standing, sleepiness, slow reflexes, loss of balance
Olmesartan	Hypertension	Low blood pressure
Oxazepam	Anxiety	Drowsiness, slow reactions, impaired balance
Oxybutinin	Urinary incontinence	Drowsiness, dizziness and blurred vision
Paroxetine	Depression	Drop in blood pressure on standing, confusion
Perindopril	Hypertension, Heart failure	Low blood pressure, drop in blood pressure on standing
Phenobarbital	Epilepsy	Sleepiness, slow reactions, unsteadiness and lack of movement control
Phenytoin	Epilepsy	Unsteadiness and lack of movement control
Pramipexole	Parkinson's disease	Delirium and drop in blood pressure on standing
Prazosin	Hypertension	Drop in blood pressure on standing
Pregabalin	Epilepsy, Neuropathic pain	Sleepiness
Prochlorperazine	Nausea, Vomiting, Vertigo	Movement disorder in long term use
Promethazine	Allergy, Urticaria	Drowsiness and blurred vision
Propranolol	Hypertension, Angina, Arrhythmia	Low blood pressure, drop in blood pressure on standing, slow heart rate
Quetiapine	Psychosis, Agitation	Drop in blood pressure on standing, sleepiness, slow reflexes, loss of balance
Ramipril	Hypertension, Heart failure	Low blood pressure, drop in blood pressure on standing
Risperidone	Psychosis, Agitation	Drop in blood pressure on standing, sleepiness, slow reflexes, loss of balance
Rivastigmine	Dementia	Fainting
Ropinirole	Parkinson's disease	Delirium and drop in blood pressure on standing
Selegiline	Parkinson's disease	Drop in blood pressure on standing
Sertraline	Depression	Drop in blood pressure on standing, confusion
Solifenacin	Urinary incontinence	Drowsiness, dizziness and blurred vision
Sotalol	Arrhythmia	Low blood pressure, drop in blood pressure on standing, slow heart rate
Tamsulosin	Benign prostatic hyperplasia	Drop in blood pressure on standing
Telmisartan	Hypertension	Low blood pressure
Temazepam	Insomnia	Drowsiness, slow reactions, impaired balance
Timolol eye drops	Glaucoma	Drop in blood pressure on standing, slow heart rate
Tolterodine	Urinary incontinence	Drowsiness, dizziness and blurred vision
Trazodone	Depression, Anxiety	Drop in blood pressure on standing, drowsiness, slow reactions, impaired balance
Trimipramine	Depression	Drop in blood pressure on standing, drowsiness, slow reactions, impaired balance
Venlafaxine	Depression	Drop in blood pressure on standing, sleepiness, dizziness, confusion
Verapamil	Hypertension, Angina, Arrhythmia	Low blood pressure, drop in blood pressure on standing
Zolpidem	Insomnia	Drowsiness, slow reactions, impaired balance
Zopiclone	Insomnia	Drowsiness, slow reactions, impaired balance

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References

1. Office for National Statistics (2019) *Estimates of the population for the UK, England and Wales, Scotland and Northern Ireland*.
2. Hertfordshire Community Foundation, (2021). 'Hertfordshire Matters – Learning Disabilities'. Available at <https://www.hertsfc.org.uk/shares/Learning-Disabilities.pdf>. (Accessed 1.3.21).
3. Heslop, P. and Hoghton, M. (2018). *The Learning Disabilities Mortality Review (LeDeR) programme*. *British Journal of General Practice*, vol 68 (suppl 1).
4. Heslop, P. Blair, P. Fleming, P. Hoghton, M. Marriott, A. and Russ, L. (2013) *Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD): Final report*. Bristol: Norah Fry Research Centre, University of Bristol. Available at <http://bristol.ac.uk/cipold/reports/>. (Accessed 23 November 2020)
5. Fuford, GE. Brown, JK. (1976) *Position as a cause of deformity in children with cerebral palsy*. *Developmental Medicine and Child Neurology*. Vol (18): 305-14
6. Department of Health (2001). *Valuing People: A New Strategy for Learning Disability for the 21st Century*. A White Paper, 2001.
7. Mencap (2005) 'Treat me right. Better healthcare for people with a learning disability'. Available at https://www.mencap.org.uk/sites/default/files/2016-08/treat_me_right.pdf (Accessed 23 November 2020)
8. Fletcher, A. and O'Brien, N. (2008). *Disability Rights Commission (DRC) Disability Rights Commission: From Civil Rights to Social Rights*. *Journal of Law and Society* Vol. 35, No. 4 pp. 520-550.
9. Mencap, (2007). 'Death by indifference. Following up the Treat me right! report'. Available at <https://www.bl.uk/collection-items/death-by-indifference-following-up-the-treat-me-right-report> (Accessed 18 October 2020).
10. Michael, J. (2008) *Healthcare for All: Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities*. London: Department of Health
11. Mansell, J. (2010) *Raising Our Sights: services for adults with profound intellectual and multiple disabilities*. Department of Health, London. Available at: https://www.mencap.org.uk/sites/default/files/2016-06/Raising_our_sights_report.pdf (Accessed 23 November 2020)
12. Clayton, S. and Goldsmith, J. (2010). *Biomechanics and prevention of body shape distortion*. *The Tizard Learning Disability Review*. 2010. Vol. 15, Issue 2, pgs. 15 – 29
13. Clayton, S. (2011). *A one year postural care training programme for the workforce supporting the needs of those with complex and continuing healthcare needs: project evaluation*. *Skills for Health*. <http://www.simplestuffworks.co.uk>
14. National Institute for Health & Care Excellence (2012) *Spasticity in under 19s: management (clinical guideline 145)* <https://www.nice.org.uk/guidance/cg145> (Accessed 23 November 2020)
15. *The Learning Disabilities Mortality Review (LeDeR) programme at the University of Bristol (2015-2021)*. Available at <http://www.bristol.ac.uk/sps/leder/uob-2015-21/#d.en.544358> (Accessed 18 March 2020)
16. Robertson, J. Baines, S. Emerson, E. Hatton, C. (2016). *Postural care for people with intellectual disabilities and severely impaired motor function: A scoping review*. *Journal of Applied Research in Intellectual Disabilities*.
17. Public Health England. (2018) *Promoting good postural care to improve health*. <https://www.gov.uk/government/publications/postural-care-services-making-reasonable-adjustments/postural-care-and-people-with-learning-disabilities>
18. *Learning Disability Mortality Review (LeDeR) Programme: Action from Learning (2019)* available at www.england.nhs.uk
19. GOV.UK. (n.d.). *Postural care services and people with learning disabilities*. Available at: <https://www.gov.uk/government/publications/postural-care-services-making-reasonable-adjustments> [Accessed 13 Oct. 2020].
20. *Skills for Health, Health Education England and NHS England*. (2019). *Skills for Health Core Capabilities Framework for Supporting People with a Learning Disability*.
21. Wright, R and Clayton, S (2020) *Postural care in the age of Covid-19* <https://www.bornattherighttime.com/wp-content/uploads/2019/10/Posture-Positive-Summary-2.pdf>
22. *Learning from lives and deaths (2021)*. *People with a learning disability and autistic people (LeDeR) policy*. Version 1.
23. NICE. (2017). *Overview: Intermediate care including reablement guidance [online]* Available at: <https://www.nice.org.uk/guidance/NG74> (Accessed 29 Oct. 2019).
24. *Mental Capacity Act (2005)*. *Code of Practice*. (n.d.). Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-codeofpractice.pdf.
25. *Care Act (2014)*. Available at: <https://www.legislation.gov.uk/ukpga/2014/23/contents>
26. *Joint Health and Social Care Self-Assessment Framework (NHS England and National ADASS (Association of Directors of Adult Social Services) (24)*
27. *Re MM (an adult) (2007) EWHC 2003 (Fam)*. (Judge Mummy). Available at <http://www.bailii.org/ew/cases/EWHC/Fam/2007/2003.html>
28. Szerletics, A. (2011). *Vulnerable Adults and the Inherent Jurisdiction of the High Court*. *Inherent jurisdiction case re vulnerable adult*. Essex Autonomy Project. Vol. 1.0
29. *Social Care Institute for Excellence (SCIE)*. (n.d.). *Dignity in care: choice and control*. Available at: <https://www.scie.org.uk/dignity/care/videos/choice-control> [Accessed 13 Oct. 2020].
30. NICE. (2015). *Decision-making and mental capacity guidance*. Available at: <https://www.nice.org.uk/guidance/ng108/chapter/Context> [Accessed 13 Oct. 2020].
31. *Local.gov.uk*. (2019). *Empowering patients, service users and communities*. Available at: <https://www.local.gov.uk/our-support/our-improvement-offer/care-and-health-improvement/integrationandbetter-care-fund/better-care-fund/integration-resource-library/empowering-patients-service-usersandcommunities>.
32. *NHS Improvement*. (2018). *Root cause analysis - using five whys*. Available at: <https://www.england.nhs.uk/wp-content/uploads/2021/03/qsir-five-whys.pdf>
33. *Nice*. (2015). *Older people: independence and mental wellbeing guidance*. Available at: <https://www.nice.org.uk/guidance/ng32>
34. *The Challenging Behaviour Foundation*, (2021). <https://www.challengingbehaviour.org.uk/understanding-behaviour/communication-sheet.html> (Accessed 21.2.21)
35. *Disability Distress Assessment Tool*. (2004). *DisDAT*. Available at: https://www.wamhinpc.org.uk/sites/default/files/Dis%20DAT_Tool.pdf [Accessed 11 December 2020].
36. Mencap (2021). Available at: <https://www.mencap.org.uk/learning-disability-explained/communicating-people-learning-disability> (Accessed 14.2.21).
37. Almeida, N. Costa, R. Ribeiro, R. (2015). *Body position influences the maximum inspiratory and expiratory mouth pressures of young healthy subjects*. *School of Health Sciences, University of Aveiro, Aveiro, Portugal*. *Physiotherapy* 101. 239–241
38. *Review of current seating practices in supporting people living with dementia in residential aged care - a pilot study*. (2012). Available at: https://dementiaresearch.org.au/wp-content/uploads/2020/01/369-final_report_review_of_seating_practices_sept_2012.pdf [Accessed 13 Oct. 2020].
39. *National Institute for Health and Care Excellence (UK) (2014)*. *The Prevention and Management of Pressure Ulcers in Primary and Secondary Care*. *NICE Clinical Guidelines*, No. 179.
40. Ganguly, J. Kulshreshtha, D. Almotiri, M. Jog, M. (2021). *Muscle Tone Physiology and Abnormalities*. *London Movement Disorder Centre, Canada*. Vol 13, p. 282.
41. Tilton, A.H. (2006). *Therapeutic interventions for tone abnormalities in cerebral palsy*. *NeuroRX* 3, 217–224 <https://doi.org/10.1016/j.nurx.2006.01.008>
42. *Hypotonia (2018)*. *NHS*. Available at: <https://www.nhs.uk/conditions/hypotonia> (Accessed 28.2.21).

43. Spasms. (2018). NHS. Available at: <https://mstrust.org.uk/a-z/spasticity-and-spasms> (Accessed 28.2.21. 80 81)
44. Kilbride, C. (2015). *Splinting for the prevention and correction of contractures in adults with neurological dysfunction: Practice guideline for occupational therapists and physiotherapists*. College of Occupational Therapists and Association of Chartered Physiotherapists in Neurology.
45. Khudadad, S. et al., (2020). A tool to prevent and manage contractures in care home residents. *Nursing Times*.
46. Prabhu, RKR, Swaminathan, N, Harvey, LA. (2013). *Passive movements for the treatment and prevention of contractures*. Cochrane Database of Systematic Reviews. Issue 12. Art. No.: CD009331. DOI: 10.1002/14651858. CD009331.pub2. (Accessed 01 March 2021)
47. Doidge, N. (2007). *The brain that changes itself: stories of personal triumph from the frontiers of brain science*. London: Penguin.
48. Keci, A, Tani, K. and Xhema, J. (2019). *Role of Rehabilitation in Neural Plasticity*. Open Access Macedonian Journal of Medical Sciences, 7(9), pp.1540–1547. pp.110–111.
49. Larsen, D.S. (2012). *Why Neuroplasticity?* Journal of Neurologic Physical Therapy. Vol 36(2). Available at: <https://journals.lww.com/jnpt/pages/articleviewer.aspx?year=2012&issue=06000&article=00012&type=Fulltext> [Accessed 2 Dec. 2019].
50. Kolb, B, Mychasiuk, R, Muhammad, A. and Gibb, R. (2013). *Brain Plasticity in the Developing Brain. Changing Brains - Applying Brain Plasticity to Advance and Recover Human Ability*, Available at: https://sites.oxy.edu/clint/physio/article/BrainplasticityinthedevelopingbrainKolb2013ProgressinBrainResearch-Chapter_2.pdf
51. Department of Health and Social Care (2019). *Physical activity guidelines: UK Chief Medical Officers' report*. Available at: <https://www.gov.uk/government/publications/physical-activity-guidelinesukchief-medical-officers-report>
52. Royal College of Occupational Therapists. (2020). *A-Z Of Activities*. Available at: <https://www.rcot.co.uk/about-occupational-therapy/living-well-care-homes-2019/a-z-activities> (Accessed 11 December 2020).
53. Dr Lee, K. (2020). *Material citizenship: the importance of functional objects in care homes whilst social distancing*. Enrich: Enabling Research in Care Homes. Available at: <https://enrich.nihr.ac.uk/blogpost/material-citizenship-the-importance-of-functional-objects-in-care-homes-whilst-social-distancing/>
54. McKenzie, K. et al., (2018). *Encouraging physical activity in people with learning disabilities*. *Nursing Times* [online]; 114: 8, 18-21.
55. WHO. (2015) *WHO: World report on ageing and health*. Available at: <https://www.who.int/ageing/publications/world-report-2015/en/>
56. JustStand.org. (2017). *The Facts Behind "Sitting Disease" and Living Sedentary*. Available at: <https://www.juststand.org/the-facts/>
57. Arva J, Paleg G, Lange M, Lieberman JT, Schmeler M, Dicianno B. (2009) *RESNA Position on the Application of Wheelchair Standing Device*. Pages 161-168 |
58. Harding T. (1997) *A life worth living: the Independence and Inclusion of older people*. Help the Aged, London.
59. Harvey JA, Chastin SFM, Skelton DA. (2015) *How sedentary are older people? A systematic review of the amount of sedentary behaviour*. *J Aging Phys Act*. 23(3): 471-87.
60. Owen N, Bauman A, Brown W. (2009) *Too much sitting: a novel and important predictor of chronic disease risk?* *Br J Sports Med*. 43:81-83
61. Fairhall NJ, Sherrington C, Cameron ID. (2013) *Mobility training for increasing mobility and functioning in older people with frailty*. *Cochrane Database Sys Rev*. Issue 5.
62. Ebrahim S, Thompson PW, Baskaran V, Evans K. (1997) *Randomised placebo-controlled trial of brisk walking in the prevention of post-menopausal osteoporosis*. Available at: <https://pubmed.ncbi.nlm.nih.gov/9271287/> (Accessed 23.4.20)
63. Skelton, D, Dinan, S, Campbell, M. and Rutherford, O. (2005). *Tailored group exercise (Falls Management Exercise - FaME) reduces falls in community-dwelling older frequent fallers (an RCT)*. *Age and Ageing*, 34(6), pp.636–639.
64. Lord SR, Sherrington C, Menz H, Clos JCT. (2007) *Falls in Older People: Risk Factors and Strategies for Prevention*, 2nd Edition. Cambridge University Press.
65. Frighi, V, Morovat, A, Stephenson, M, White, S, Hammond, C, Goodwin, G. (2014). *Vitamin D deficiency in patients with intellectual disabilities: Prevalence, risk factors and management strategies*. *The British journal of psychiatry: the journal of mental science*. Vol, 205(6).
66. NHS. (2020). *Vitamins and minerals – Vitamin D*. Available at: www.nhs.uk (Accessed 16.5.21)
67. NHS. (2021). *Chronic obstructive pulmonary disease*. Available at: <https://www.nhs.uk/conditions/chronic-obstructive-pulmonary-disease-copd/> (Accessed 16.5.21)
68. NHS. (2021). *Chronic fatigue syndrome*. Available at: <https://www.nhs.uk/conditions/chronic-fatigue-syndrome-cfs/treatment/> (Accessed 16.5.21)
69. *Mental Capacity Act (2005). Mental Capacity Code of Practice. Code of practice giving guidance for decisions made under the Mental Capacity Act 2005*. Available at: <https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice> (Accessed 14 October 2020)
70. NICE (2015). *Older people: independence and mental wellbeing. NICE guideline*. Available at: <https://www.nice.org.uk/guidance/ng32/resources/older-people-independence-andmentalwellbei-ng-1837389003973>
71. NHS. (2021). *Sepsis*. Available at: www.nhs.uk/conditions/sepsis (Accessed 16.5.21)
72. Deeny, S, Thorlby, R. and Steventon, A. (2018). *Briefing: Reducing emergency admissions: unlocking the potential of people to better manage their long-term conditions*. Available at: <https://www.health.org.uk/publications/reducing-emergency-admissions-unlocking-the-potential-of-people-to-better-manage-their-long-term-conditions>
73. Hertfordshire Community Learning Disability Nursing Service, (2019). *Top to Toe Handbook - A guide to support early recognition of the signs and symptoms of ill health in people with learning disabilities*
74. Restore2. (2018). Available at: <https://wessexahsn.org.uk/projects/329/restore2> (Accessed 2 September 2020)
75. NHS England (2014). *NHS England. Making it happen: Multi-disciplinary team (MDT) working*. England. nhs.uk.
76. NHS England (2019). *Introducing bedside vital signs devices at Imperial College Healthcare NHS Trust. The Atlas of Shared Learning, Case study. Introducing bedside vital signs devices at Imperial College Healthcare NHS Trust4. Leading Change, Adding Value Team (Nursing, midwifery and care)* <https://www.england.nhs.uk> (Accessed 11.8.20)
77. NHS England, (2017). *Involving people in their own health and care: Statutory guidance for clinical commissioning groups*. Available at: <https://www.england.nhs.uk/wp-content/uploads/2017/04/ppp-involving-peoplehealthcare-guidance.pdf> (Accessed 17.11.20)
78. *Medicines and Falls Risks (2011) Medicines and Falls Hospitals guidance*. John Radcliff Hospital.

Additional Resources:

- Living well through activity in care homes: the toolkit (2015), The Royal College of Occupational Therapy
<https://www.rcot.co.uk/file/940/download?token=WZIMG-fB> · PDF file
- A-Z of activities, The Royal College of Occupational Therapy
<https://www.rcot.co.uk/about-occupational-therapy/living-well-care-homes-2019/a-z-activities>
- NICE, 2018. <https://www.nice.org.uk/guidance/ng93/resources/learning-disabilities-and-behaviour-that-challenges-service-design-and-delivery-pdf-1837753480645>

Further Help

Many people with a learning disability can use or recognise some signs

- Signalong - The Communication Charity - signalong.org.uk
- Makaton - www.makaton.org
- Visit the British Deaf Association website to find out more about BSL.
- Talking Mats are a communication system that uses symbols and other images.
- Widgit produce software symbols to help with communication and accessibility.
- Symbol World is a website run by Widgit for symbol users that includes nursery rhymes, stories and a monthly magazine.

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