

Welcome

Growing Older with Learning Disabilities (GOLD)
The impact of aging for people with a learning
disability and complex physical disability.

We'll be starting shortly! Why not introduce yourselves in the chat?



Growing Older with Learning Disabilities

- Supporting people to live long, happy and healthy lives.
- Webinars, conferences and workforce development
- National Steering Group is made up of professionals, experts with experience, service providers and experts in the field



Future events

GOLD conference, 30th September 2022

BILD's Growing Older with Learning Disabilities (GOLD) network is delighted to announce early bird booking is now open for the 2022 Ageing Well with Learning Disabilities Conference.

Held in Birmingham's Crown Plaza Hotel on 30 September, with attendees also having the option to attend online, the conference will feature a range of fantastic keynotes from professionals working in the field and people with lived experience, exploring best practice in supporting people as they age.

To find out more and register, please go to: <https://bit.ly/GOLDconf22register>

Agenda

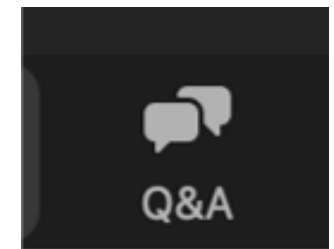
Item	Speaker	Time
Introduction from our chair	Lindsey Allen, Bild Learning Disability and Autism Manager	5 minutes
Guest speakers' presentation	David Standley; Clinical Specialist Physiotherapist Guys & St Thomas' NHS Foundation Trust Surabhi John; Specialist Physiotherapist Southwark, Lambeth and Lewisham Adults with Learning Disability Team	45 minutes
Q&A	All invited to participate	10 minutes

Housekeeping guidance

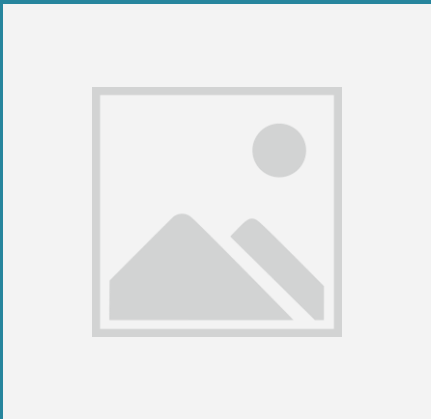
- This webinar will be recorded and an edited version will be shared with Bild members. The Q&A and any confidential discussion / feedback will be removed from the shared recording.
- Any discussion via the chat function will not be included in the recording
- Please do not take pictures or record parts of the webinar yourself
- Please be mindful this is a public forum if you decide to contribute to the session, whether that's in the Q&A at the end, or in the chat
- This is a kind and supportive space

Zoom guidance

- Please use the Q&A function to ask questions to the panel
- Please use the chat box to introduce yourself and discuss topics with the other participants



Ageing with a complex physical disability



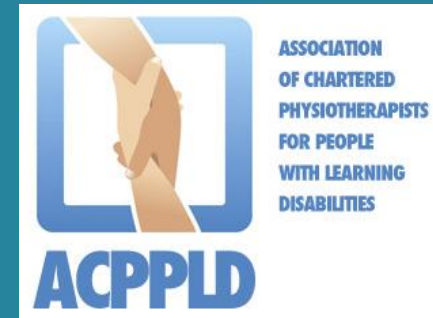
David Standley

Clinical Specialist Physiotherapist
Guy's and St Thomas' NHS Foundation Trust
Research and Development Officer ACPPLD NEC
Co-author of Standards of Practice for Physiotherapists
working with People with a Learning Disability



Surabhi John

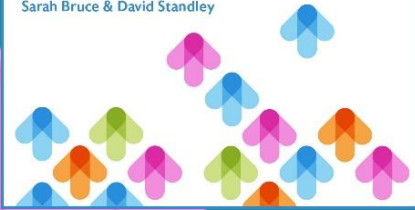
Specialist Physiotherapist
Guy's and St Thomas' NHS Foundation Trust



Standards of Practice for Physiotherapists

Working with adults with a learning disability

Sarah Bruce & David Standley



Guy's and St Thomas'
NHS Foundation Trust

Aims



- **Recognise that ageing happens to us all and is inevitable! But the way we age is effected by our health and lifestyle choices! People with a complex physical disability will need support to make these choices!**

Content:

- What is a complex physical disability?
- Normal ageing process
- Ageing with a complex physical disability
- How can you slow the ageing process?

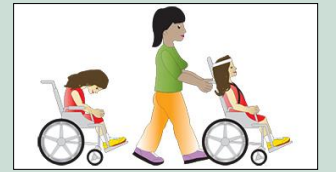
People with a Complex Physical Disability

- Have severe physical disabilities which affects all four limbs and their trunk, resulting in postural abnormalities and movement disorders.
- Individuals require wheelchairs and assistive devices to mobilise and maintain themselves upright against gravity (GMFCS level 4 and 5).
- People with complex physical disability can present with a learning disability anywhere on the continuum from mild to profound.



GMFCS level IV

GMFCS level V



People with complex physical and learning disabilities



	Morbidity and mortality	Common conditions
Non – progressive neurological conditions	Associated with the development of secondary complications, and are not, in the main, the direct manifestation of the pathological impairment	Severe Cerebral palsy Spinal bifida Chromosomal abnormalities Traumatic brain Injury/neurological event in childhood
Progressive neurological conditions	Associated with the trajectory of the neurological condition and the development of secondary complication	Duchene muscular dystrophy Leukodystrophies Multiple Sclerosis Motor Neuron Disease

Normal Ageing



Name 2 things you associate about ageing.



Go to www.menti.com and use the code **1159 8134**

Effects of Ageing

CV
system

Skin

Bones,
joints and
muscles

Bladder
and
urinary
tract

Digestive
system

Memory
and
thinking
skills

Eyes and
ears

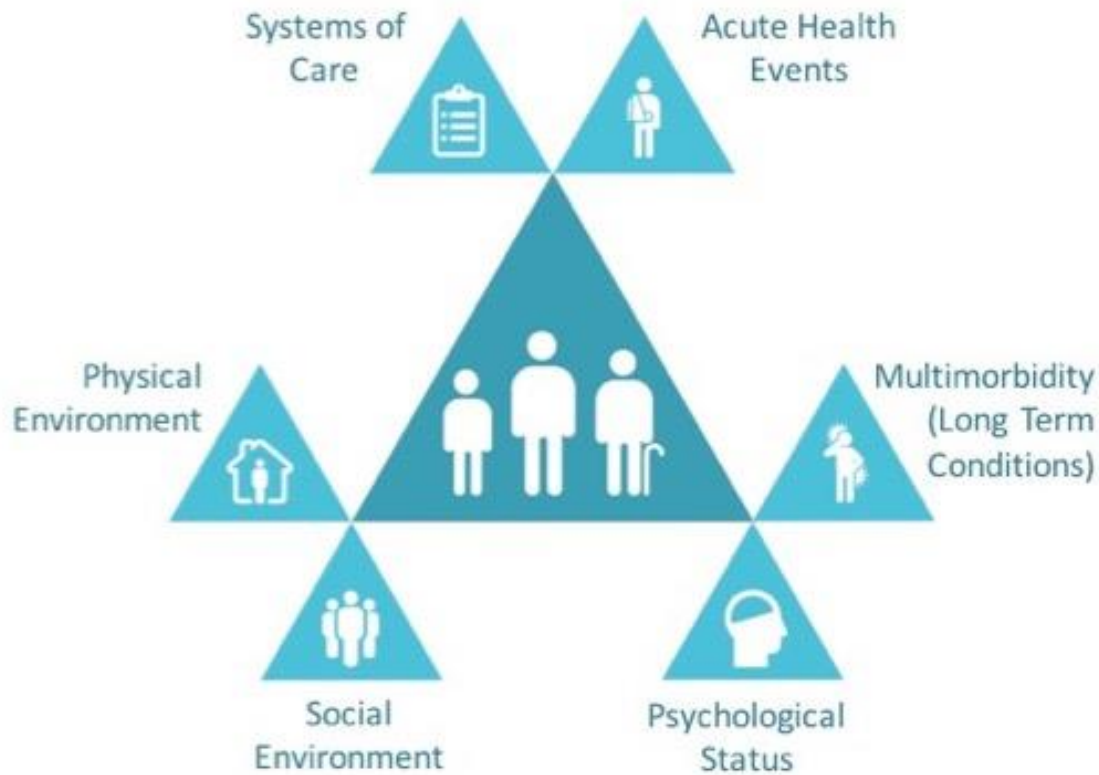
Weight

Fatigue

Menopause

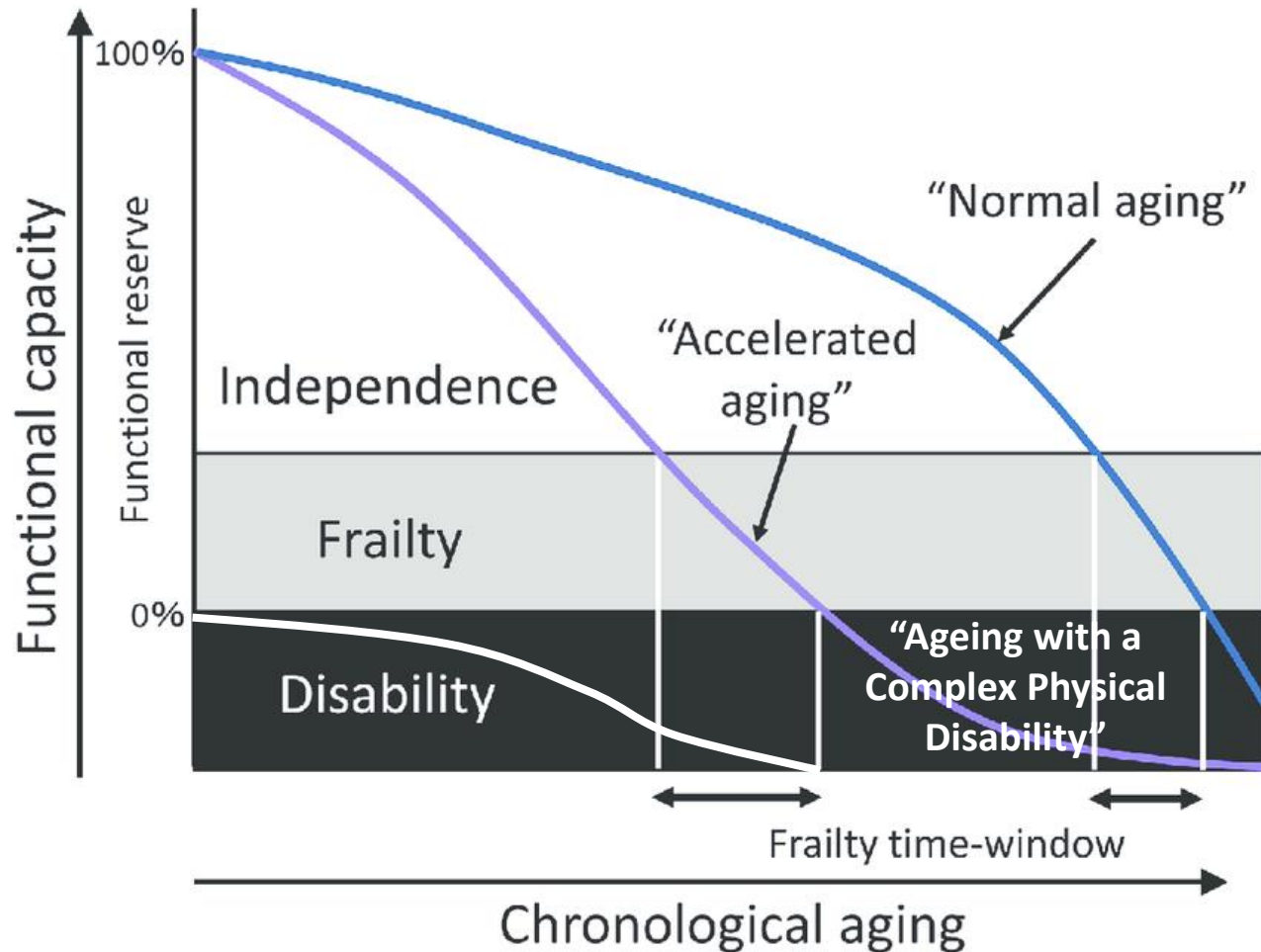
65 year old onwards

Ageing is multifactorial and not solely dependent on age



The Iron Nun still going strong at age 88

Accelerated Ageing, Premature Ageing or Early Frailty

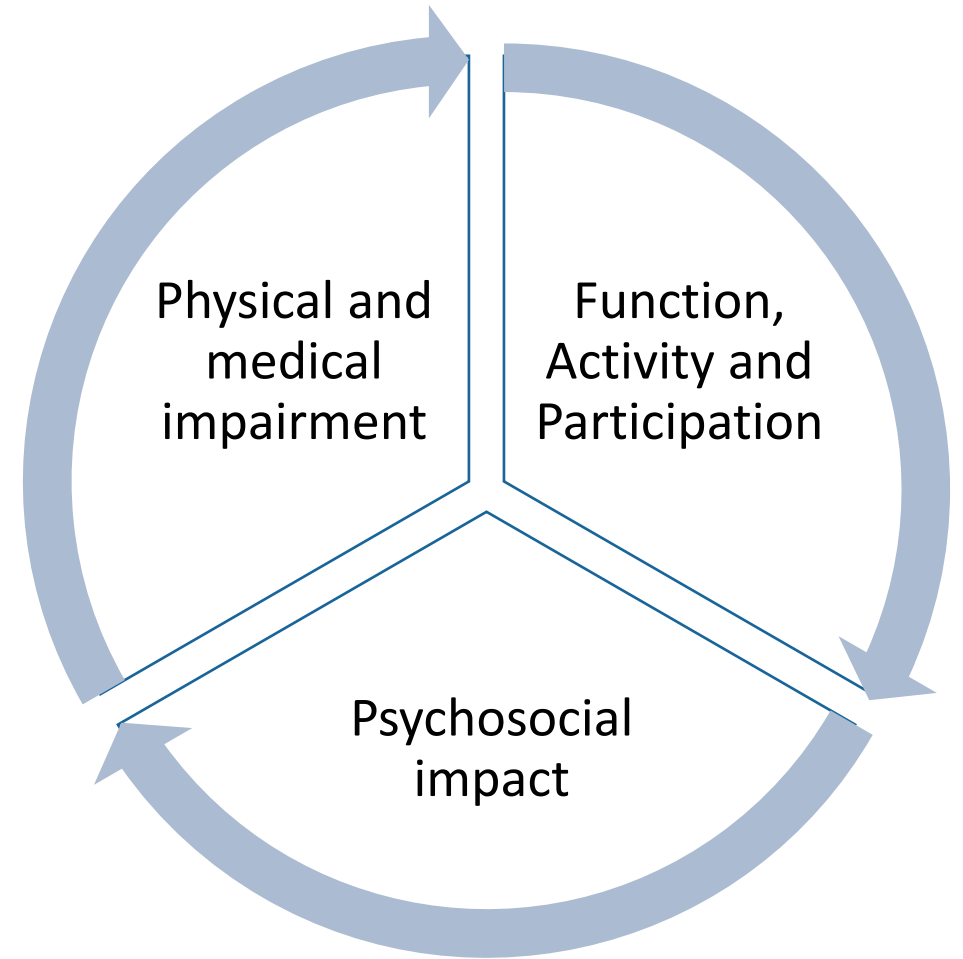


Frailty is most often defined as aging-related physiological decline, characterised by marked vulnerability to adverse health outcomes. i.e People who are frail are at risk of serious health decline from stressors such as infections that would otherwise be minor.

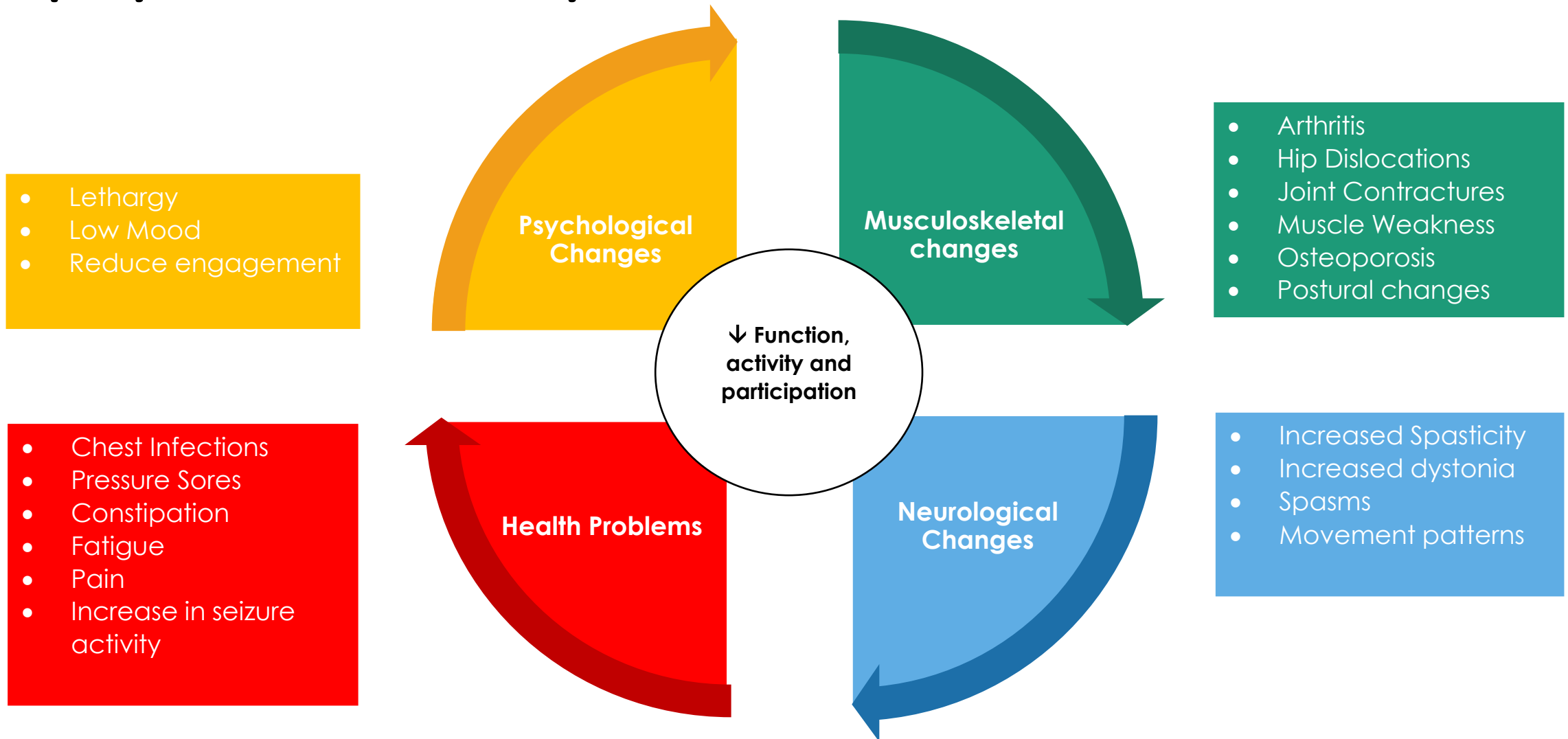
Disability is an impairment of the body or mind that makes it more difficult for the person to do certain activities (**activity limitation**) and interact with the world around them (**participation restrictions**).

Ageing with a complex physical disability and Learning Disability

- People with a Learning Disability tend to become less mobile, more frail and die at an earlier age than people without Learning Disability.
- ‘People with a Learning Disability over 50 had frailty scores similar to most elderly people over 75 years old’.
- People with complex physical disability experience the same age related changes as non-disabled people. But, changes occur much earlier.
- The life expectancy of people with complex physical disability is much shorter than the general population. Factor such as the severity of impairment, number of health conditions, mobility restrictions, feeding difficulties, seizures, cognitive function and respiratory function all effect the individual’s life expectancy.



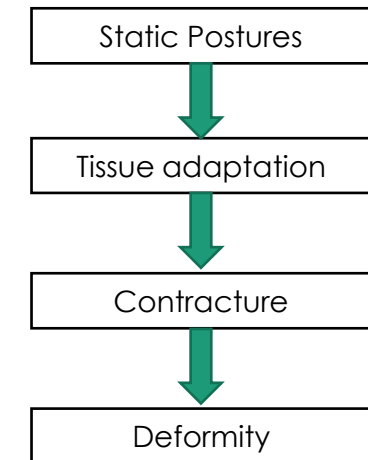
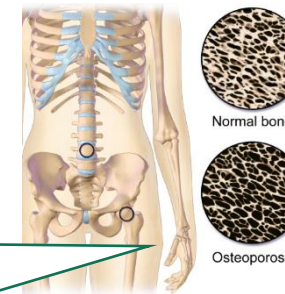
Ageing related changes in people with complex physical disability



Musculoskeletal Changes with Ageing

Tissue:	Change and impact:
Bone	Reduced bone density, Osteoporosis and Osteopenia, Low impact fragility fractures.
Articular Cartilage	Degeneration joint surface and capsule, Osteoarthritis, Pain
Tendons, Ligaments and Joint Capsule	Reduced flexibility and ten... s, pain
Healing	

Musculoskeletal impairments are among the most prevalent and symptomatic health problems of middle and old age



Pain and Discomfort

“Adults with cerebral palsy have **higher levels of pain and fatigue** than adults without cerebral palsy”

#StampOutTheGap

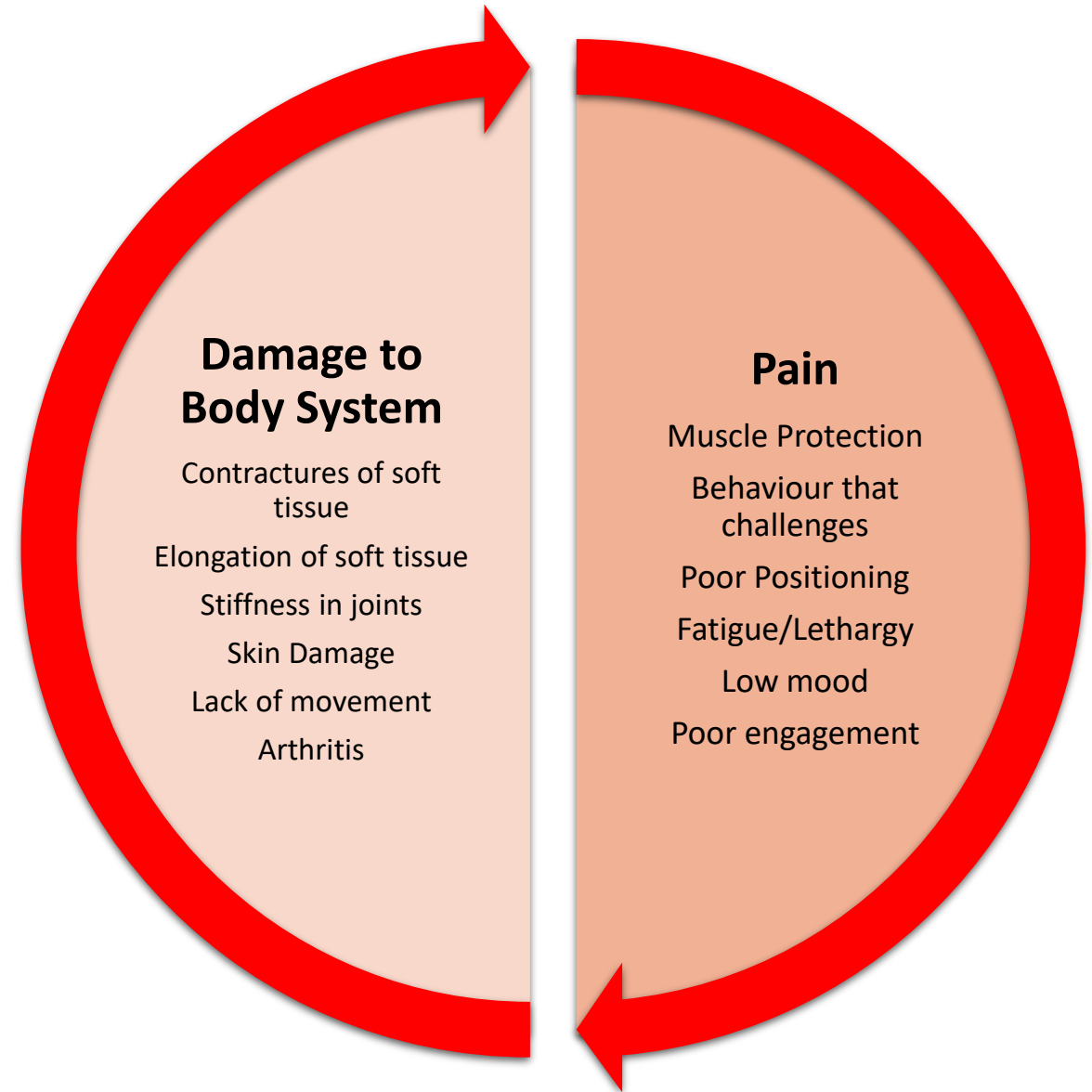
adult cerebral palsy hub

PAIN

3 in 4

The infographic features a green background on the left with a white quote and a small logo. On the right, a white background has a green header with the word 'PAIN', a blue lightning bolt icon in a circle, and the text '3 in 4' below it.

The effects of this hidden pain can be distressing and damaging



Fatigue

".....Fatigue is one of the most frequent, and pervasive of symptoms for people with Cerebral Palsy, and often very misunderstood by people outside our community. Understanding and managing fatigue can be one of the most crucial factors in living your best life...."

- Fatigue affects up to 60% of adults with Cerebral Palsy, and can dominate how they live their daily lives.
- Fatigue is different from tiredness – it is not just about getting more sleep.
- People with complex physical disability may have to use 3-5 times as much energy to perform the same tasks because of the way they move, their muscle control and the concentration they need to exert.



Contributors to fatigue

- Disturbed sleep
- Higher level of muscle activity 'at rest'
- Seizures
- Breathing problems
- Inadequate and unhealthy eating
- Dehydration
- Poor positioning
- Increased demand for energy needed to do things
- Decreased physical fitness resulting in muscle weakness and limited endurance
- Some medications have a sedating affect, contributing to the sensation of fatigue.
- Drowsiness is a commonly reported side effect of many oral drugs used to treat increased muscle tone such as spasticity or dystonia.



People with complex physical disability will often present with a number of these contributing factors!! And they increase as they age!!

Impact of ageing on network of care



- Increase in the care needs of the person as they age
- Increase in the manual handling and physical care need
- Carers will have to develop new knowledge and skills to manage the additional health needs and may find their roles change.

ALSO.....

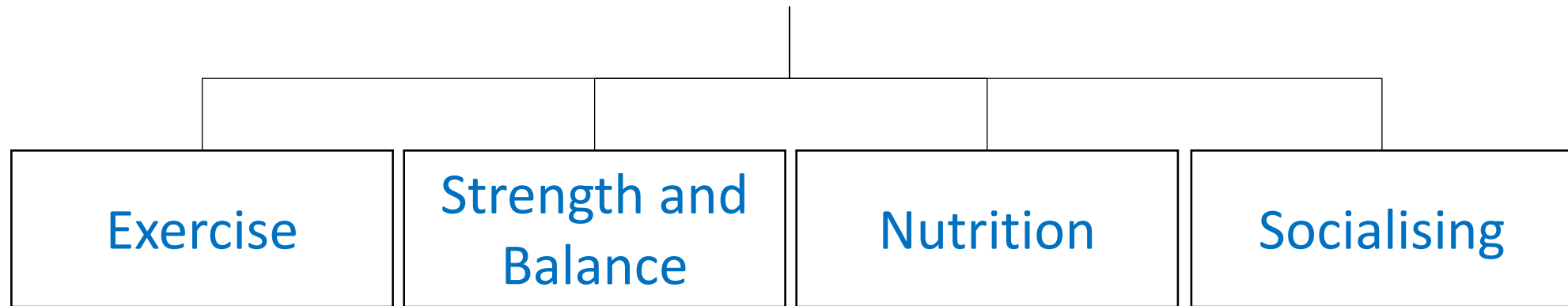
- Many people with a complex physical disability are cared for by their parents therefore whilst they get older so to are the carers.
- The impact of providing physical care for a person with a disability throughout their life time can cause age related changes such as arthritis and back pain.
- **It is important for carers to look after their own health and to ask for additional help and support.**



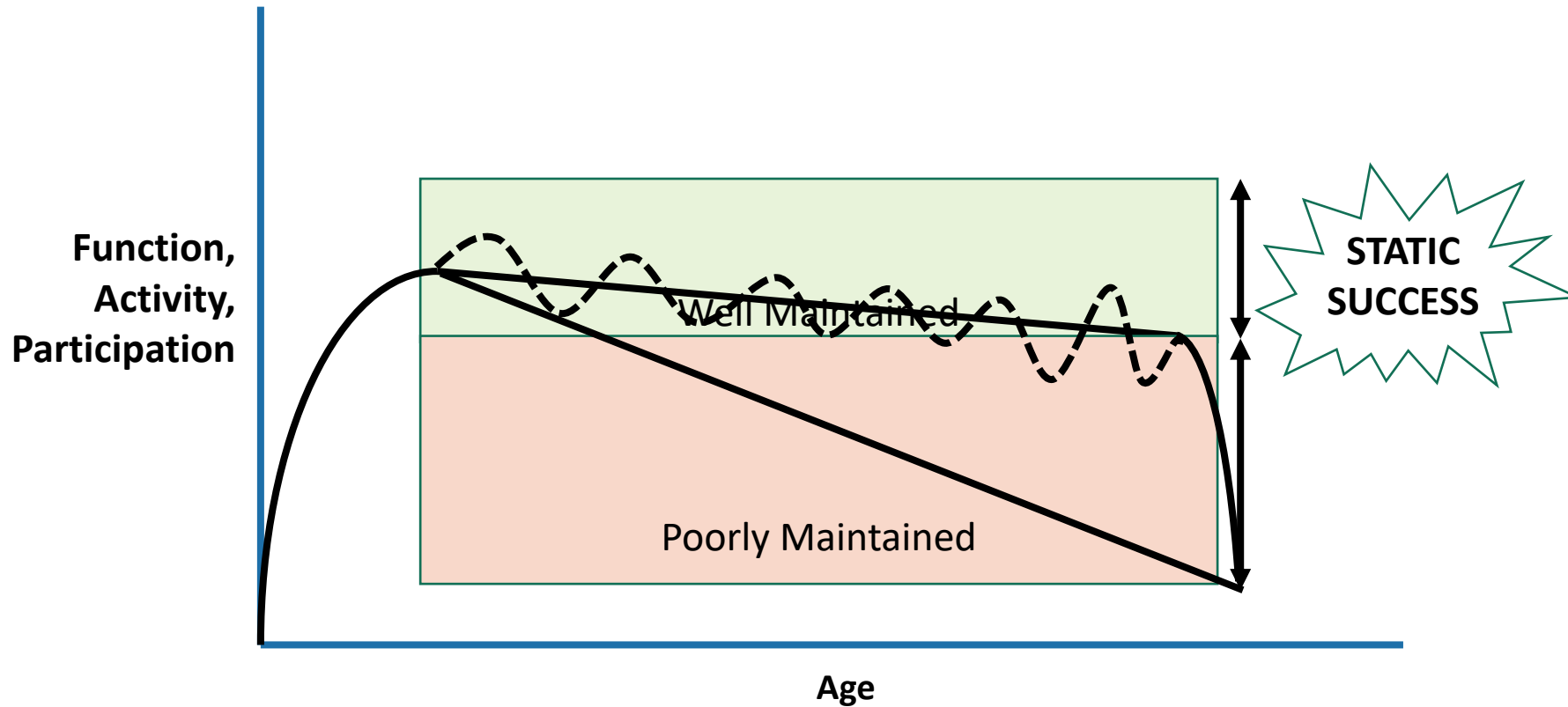
How can you influence the ageing process?



The frailty state for an individual is not static; it can be made better and worse' (Fit for frailty, 2014)



Principle of Complex Physical Disability Management

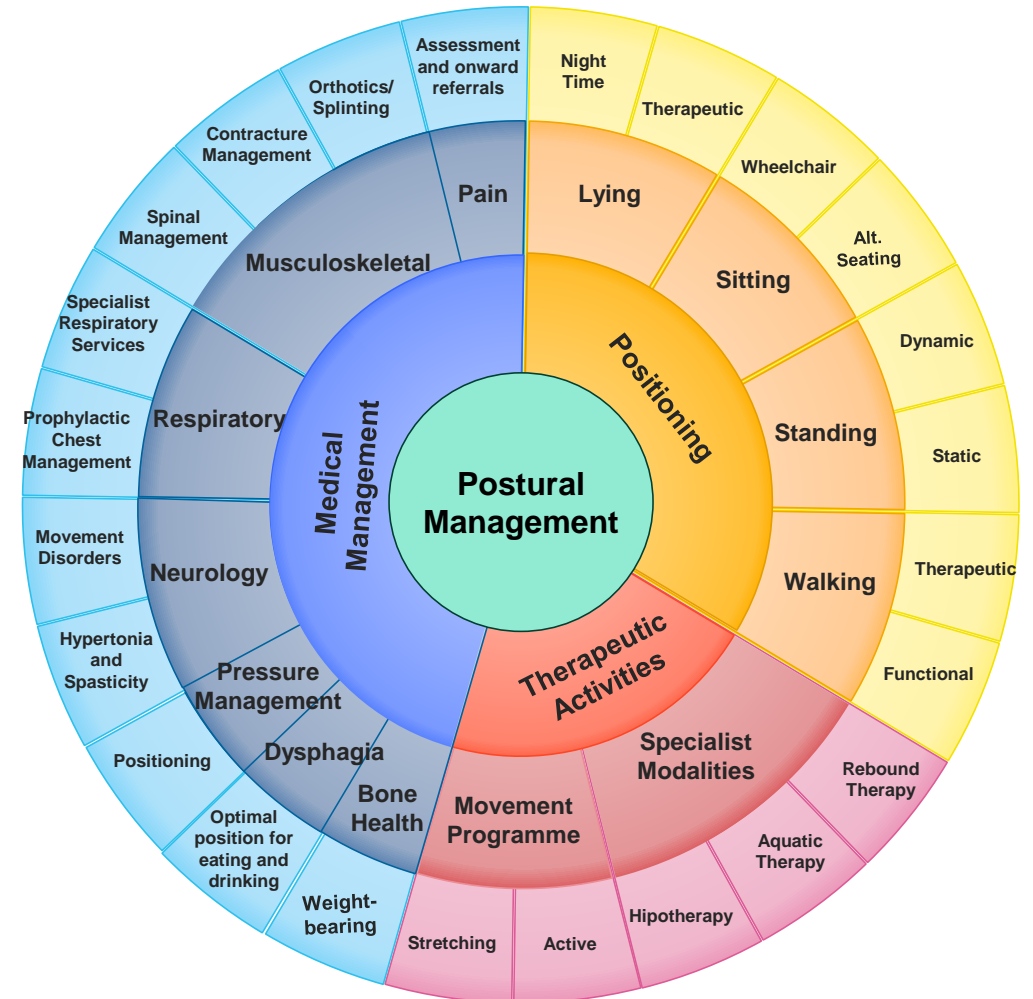


Examples of Management Approaches

- Musculoskeletal Changes
- Pain
- Fatigue

Postural Management

A postural management programme is a planned approach encompassing all activities and interventions which impact on an individual's posture, health and physical presentation so as to promote and maintain function; prevent and reduce body shape distortion and reduce the impact of associated secondary complications



Pain Management

It can be difficult to identify, localise and diagnose pain in people with a learning disability.

<u>Pharmacological:</u>	<u>Non-Pharmacological:</u>
<ul style="list-style-type: none">• Identify and treat presenting problem• Medication – Analgesia, Antispasmodic drugs, Botox, Laxatives, etc...	Physiotherapy Muscle massage Acupuncture Ice packs and heat therapy Hydrotherapy Pacing Positioning Movement



Fatigue Management

- Rule out medical causes of fatigue such as diabetes, heart disease, thyroid disease and sleep apnoea.
- Energy conservation techniques

“It is important to learn strategies to manage your energy. You need to begin to understand how much energy realistically you have in a day and how to prioritise the tasks you want to achieve.”

<https://upmovement.org.uk/live-well/fatigue/>

- Fitness and exercise to improve strength and endurance
- Proper nutrition and hydration
- Sleep management

Who can help?



General Practitioner (GP)

Dietician

**Speech and
Language
Therapist
(SALT)**

Physiotherapist

**Occupational
Therapy**



Network of Care

Nurse

Final Thoughts



- It can be a very difficult to think about the future.
- Ageing happens to us all! But the way we age is effected by the health and lifestyle choices we make throughout our lives!
- People with a complex physical disability will need help to age well
- There is help available to help reduce the impact of ageing
- Therefore, please seek help from your doctor or healthcare professionals.



QUESTIONS

The word "QUESTIONS" is written in large, bold, white, sans-serif capital letters with a slight 3D effect. It is centered on a white rectangular background. Surrounding the text is a vibrant collage of various question marks in different colors (blue, yellow, red, green, purple, pink, orange) and geometric shapes (circles, squares, triangles) in the same color palette. The background of the entire slide is a light peach or beige color.

Thank you for joining us!

bild

If you require any further information about our speakers today, please contact hello@bild.org.uk

Future webinars

- **Trauma informed care in adult health and social care -**
Wednesday 13th July, 12.00-1.30pm
- **GOLD: Supporting people with profound and multiple learning disabilities** – Tuesday 19 July, 12.00-1pm
- **Trauma informed care and the legal system -** Wednesday 20 July, 12.30-2pm

To find out more and register, please go to: www.bild.org.uk/webinars

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Find out more about Bild

www.bild.org.uk



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Join us!

Become a Bild member to access resources, webinar recordings and discounts on workforce development programmes, conferences and events

www.bild.org.uk/membership

Find out more about GOLD

<https://www.bild.org.uk/growing-older-with-learning-disabilities-gold/>

About GOLD

We are exploring the opportunities and challenges of an ageing population of people with learning disabilities. Visit our web page to find out more.