

ABPN Webinar Series

Supporting Children with Complex Disabilities: 24 Hour Postural Care

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7th May 2025

Sarah Clayton

Financial Disclosure

I am a salaried, full-time employee of Simple Stuff Works, a therapeutic positioning equipment manufacturer

I am a Director of Goldsmith and Goldsmith and am paid to provide measurement of body symmetry and consultancy to privately funded clients

Goldsmith and Goldsmith are paid to present both online and face to face training for Born at The Right Time Ltd

Goldsmith and Goldsmith are paid to provide coaching for paediatric therapists by Clinical Excellence Online

A brief history

1998 – 2000 The Mansfield
Project S Goldsmith

2007 Simple Stuff Works

2008 Carnaby and Pawlyn –
Nursing Complex Needs

2010 The Patterns of Body
Shape Distortion – Tizard J
Goldsmith and S Hill

2011 Workforce training
strategy – Skills for Care

2013 Confidential Inquiry into
Premature Deaths of People
with Learning Disabilities

2004 Postural Care CIC
Training



2011 Simple Stuff Works wins
BHTA Best Established Product
Award

2013 Living Local – NHS
Safeguarding Report



2018 Salford Postural Care
Study with older adults

2024 First Paediatric Postural
Care Masterclass – many more
to come!

2023 Clinical Excellence Online
coaching platform for
paediatric therapists

2021 Cradle to Grave 6 week
CPD online training programme
launched

2020 Posture Positive

2021 Postural Care Strategy for
Scotland

2018 NHS Reasonable
Adjustment Guidance

Session objectives:

To know a basic definition of postural care

To identify key components of postural care

To suggest some practical strategies for nurses and families

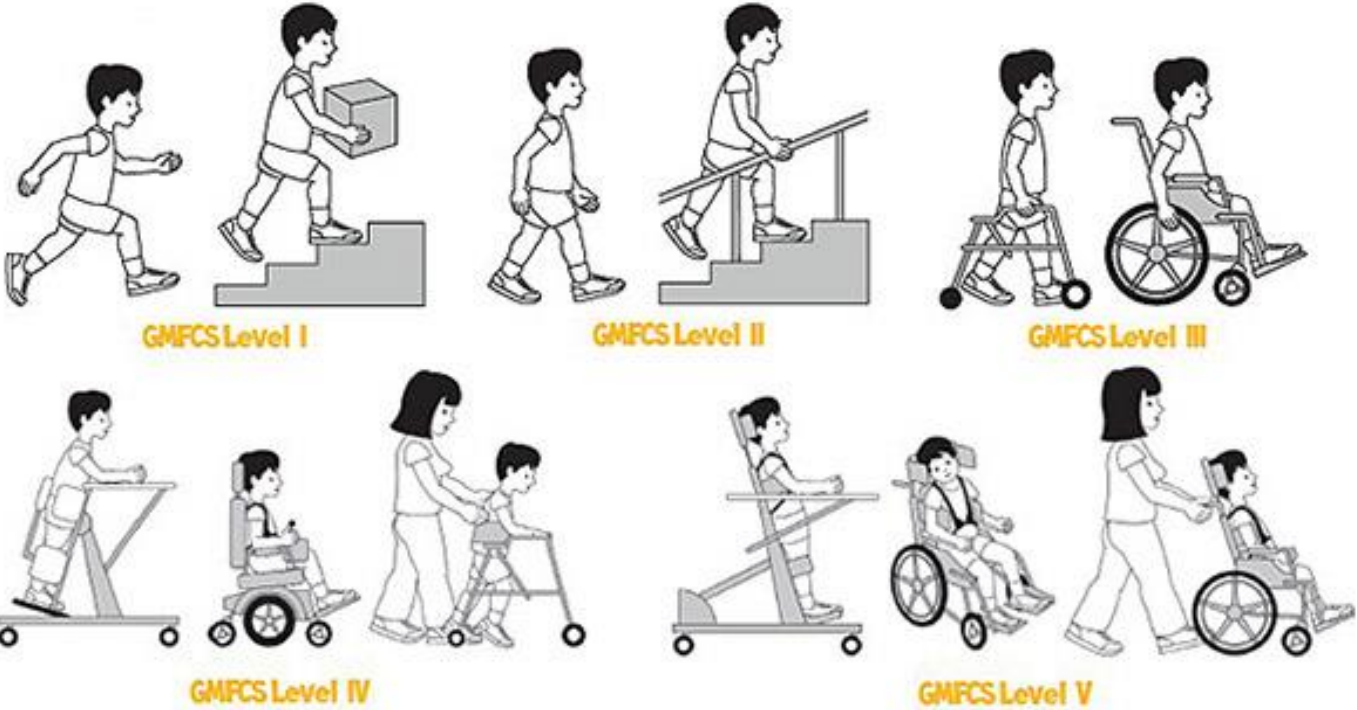
To identify common challenges for those providing postural care

Signposting to further resources and support

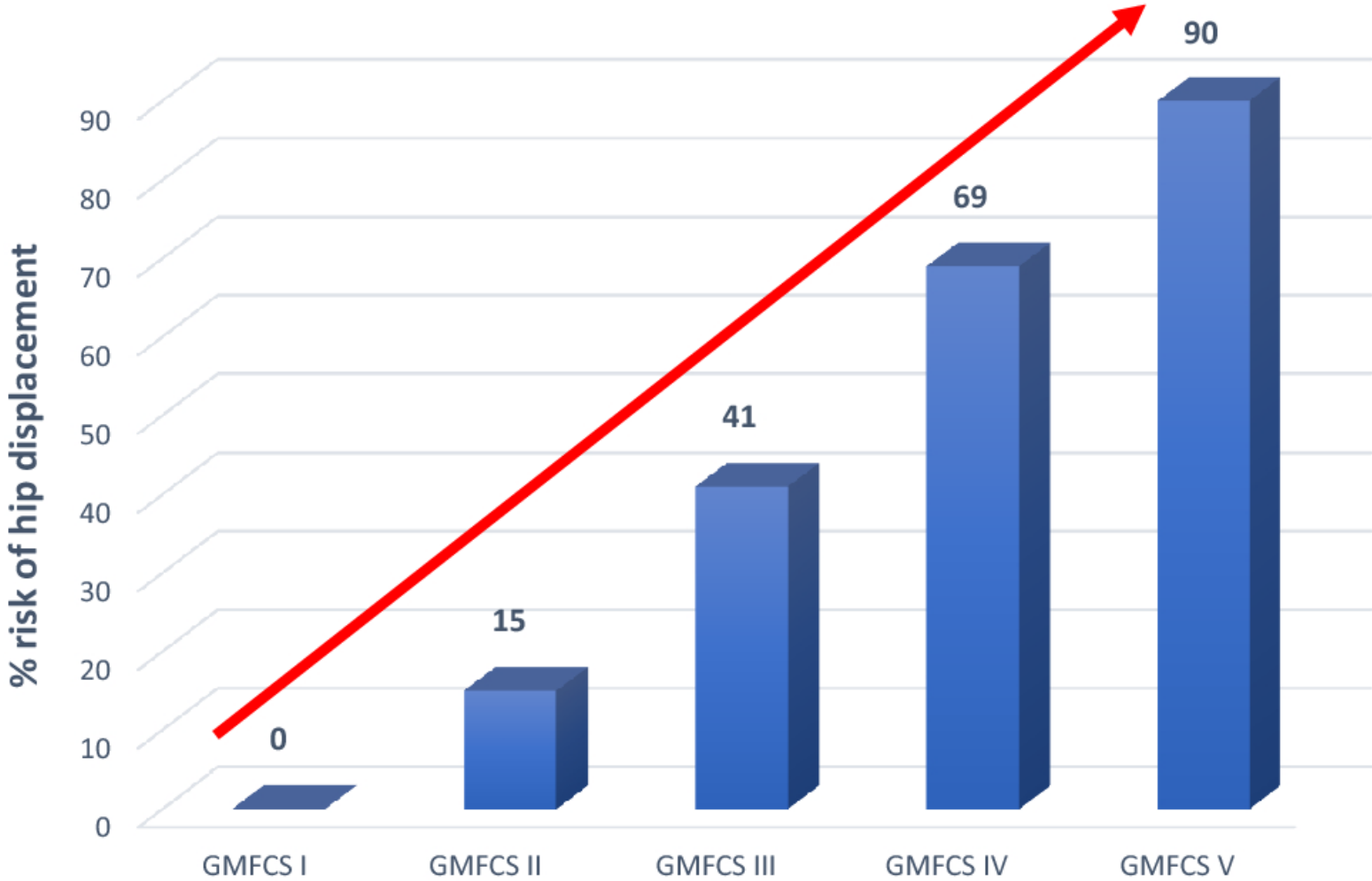
To know a basic definition of postural care

What is 24 hour postural care?

24-hour postural care is the continuous support of a person's body **day and night** to protect body shape, improve comfort, and prevent complications like pressure injuries and contractures

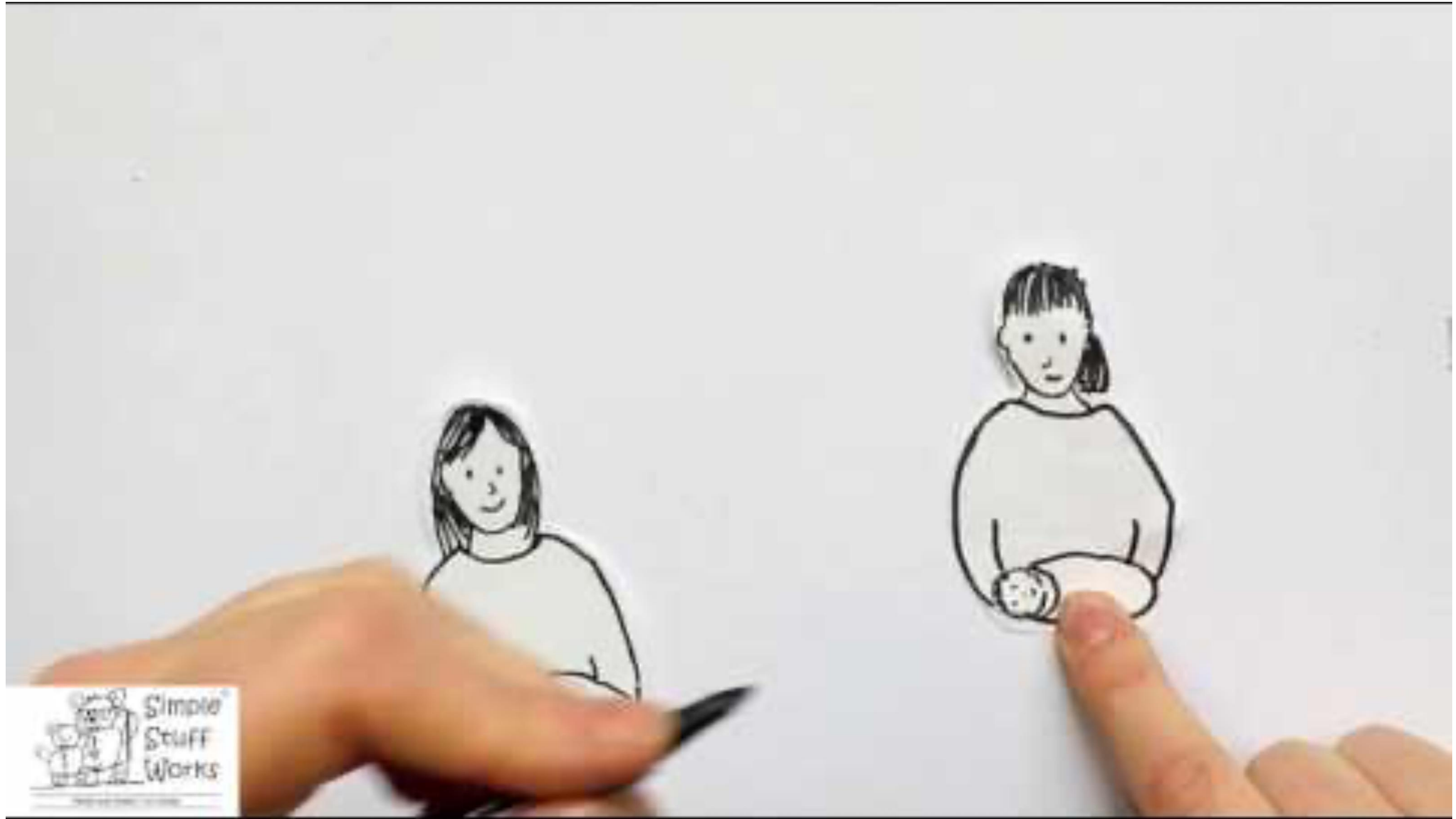


Risk of Hip Displacement related to GMFCS Levels



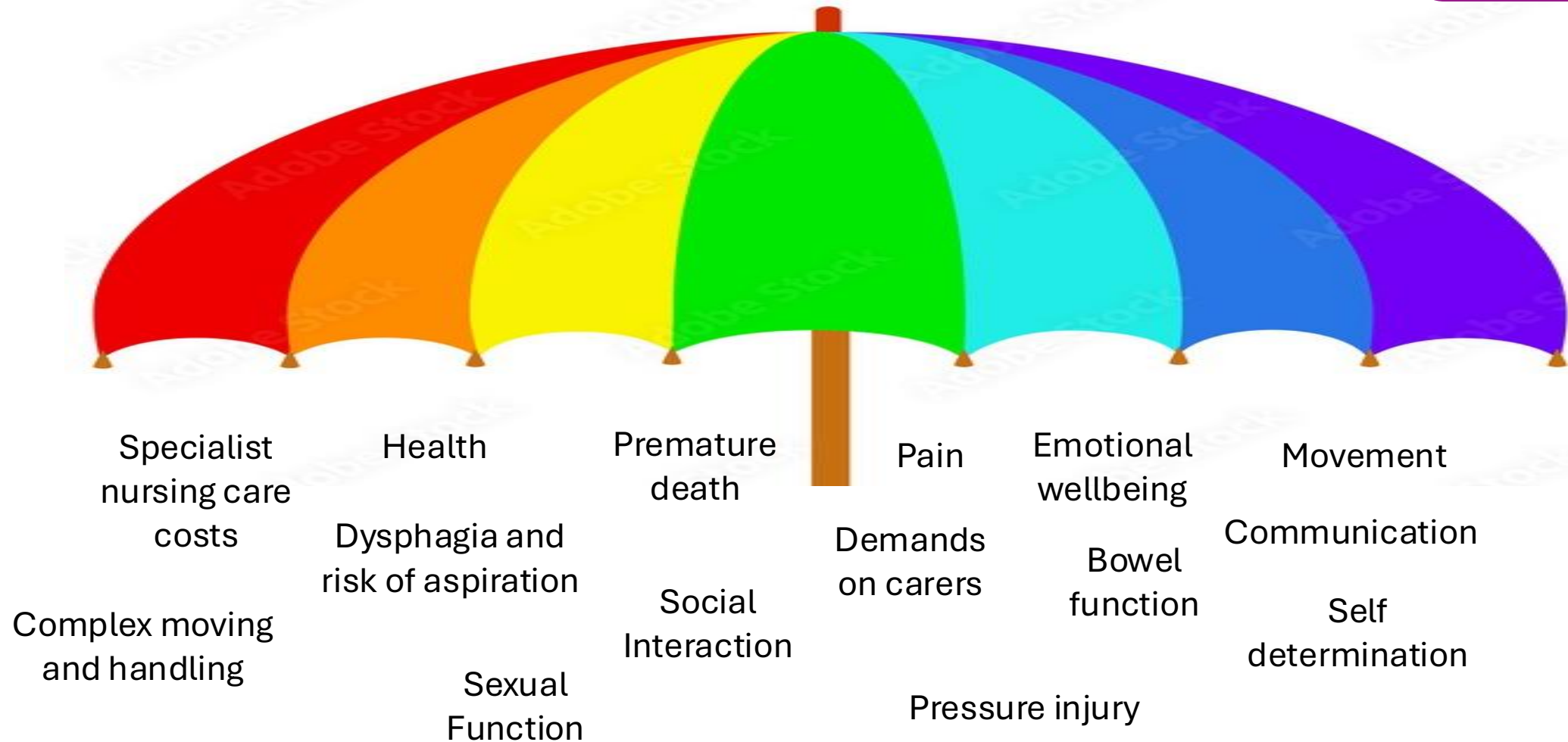
To know a basic definition of postural care

Aroojis, A., Mantri, N. & Johari, A.N. Hip Displacement in Cerebral Palsy: The Role of Surveillance. *JOIO* 55, 5–19 (2021). <https://doi.org/10.1007/s43465-020-00162-y>

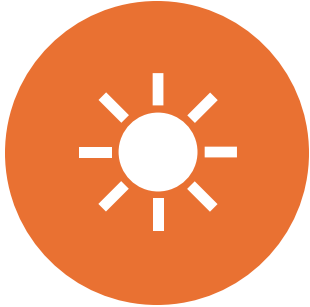


Why protect body shape?

To know a basic definition of postural care



To identify key components of postural care



DAYTIME POSITIONING

Sitting
Standing
Lying
Mobility Aids



NIGHTTIME POSITIONING

Supported lying
Usually most influential position
Leads to predictable changes in body shape



TRANSITIONS AND MOVEMENT

Changing position regularly
Movement to support learning and development



EQUIPMENT AND ASSISTIVE DEVICES

Sitting
Standing
Lying
Mobility Aids
Interaction with all other aids to daily living – hoist, communication, feeding...

To identify key components of postural care

Assessment and identification of goals

Equipment Provision

Review



Implementation

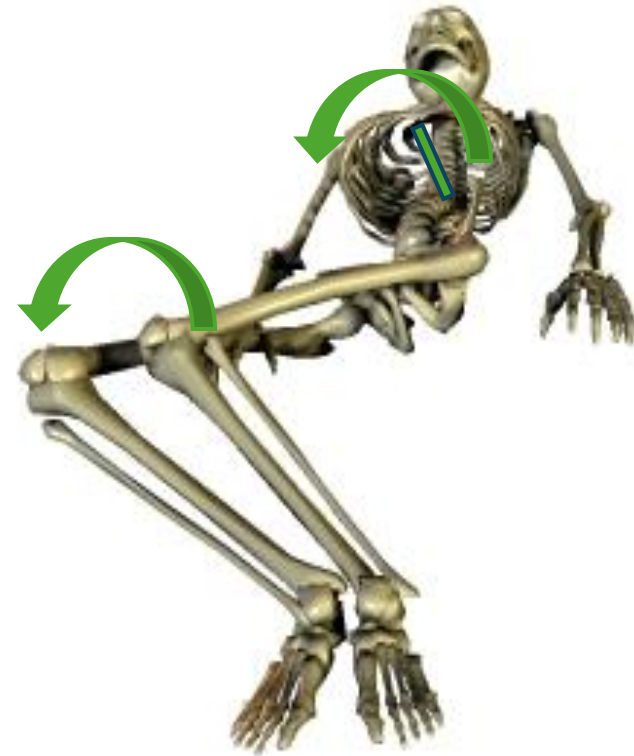
Changes in body shape are highly predictable
With predictability comes opportunity to track a different course
With opportunity comes responsibility

Windsweeping

To identify key components of postural care



Windswept **LEFT**
Clockwise chest
rotation



Windswept **RIGHT**
Anti - Clockwise chest
rotation

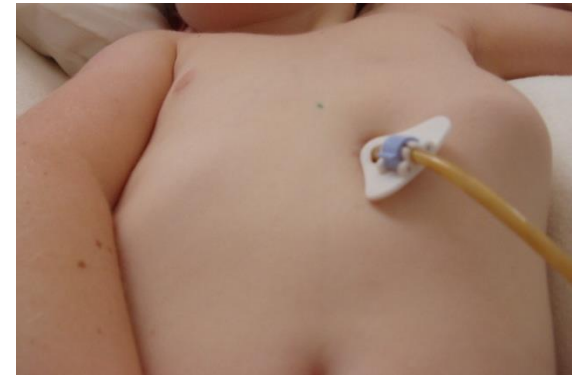
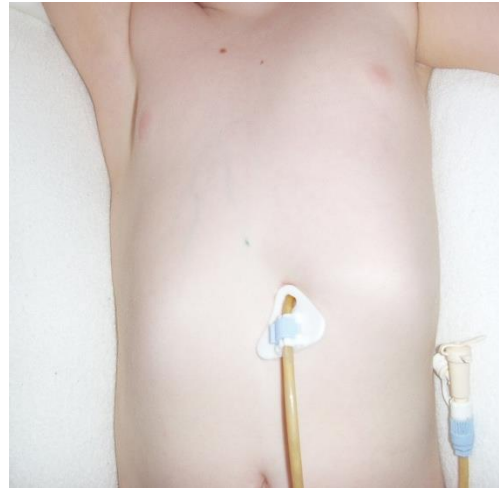


To identify key components of postural care



De-rotating the Chest

To identify key components of postural care



De-rotating the Chest

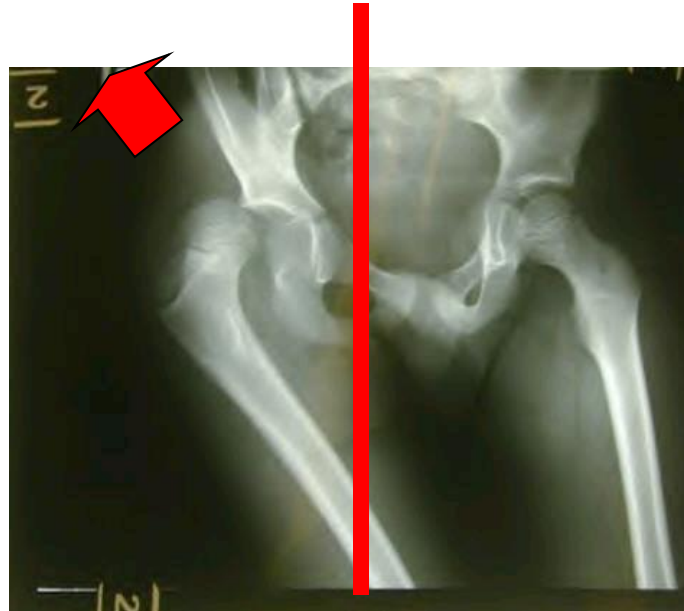
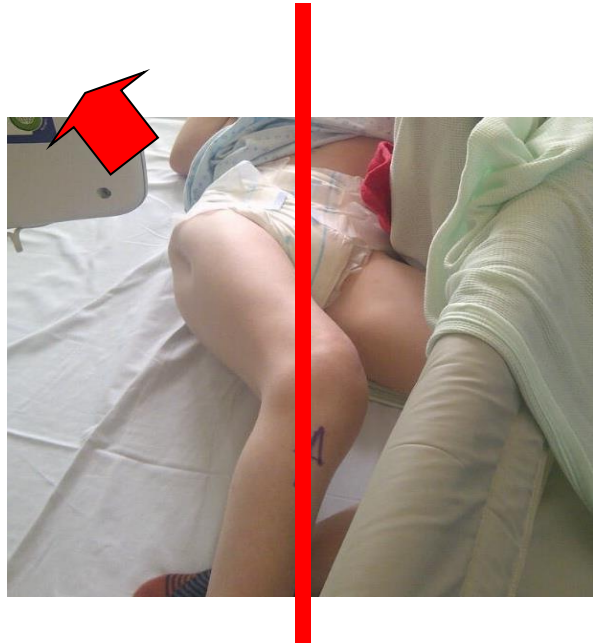
To identify key components of postural care



This young man is 25 years old
The photographs are taken 3 months apart

The direction of dislocation will depend on the position the person lies in as a habit

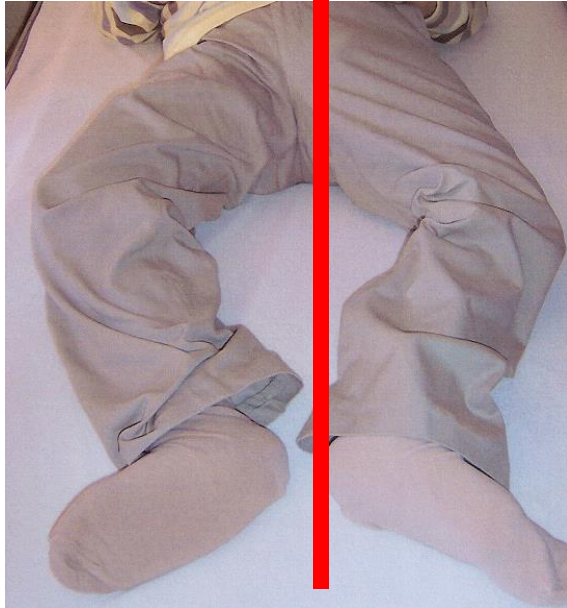
To identify key components of postural care



If the leg is crossing the midline the hip will tend to dislocate posteriorly or backwards

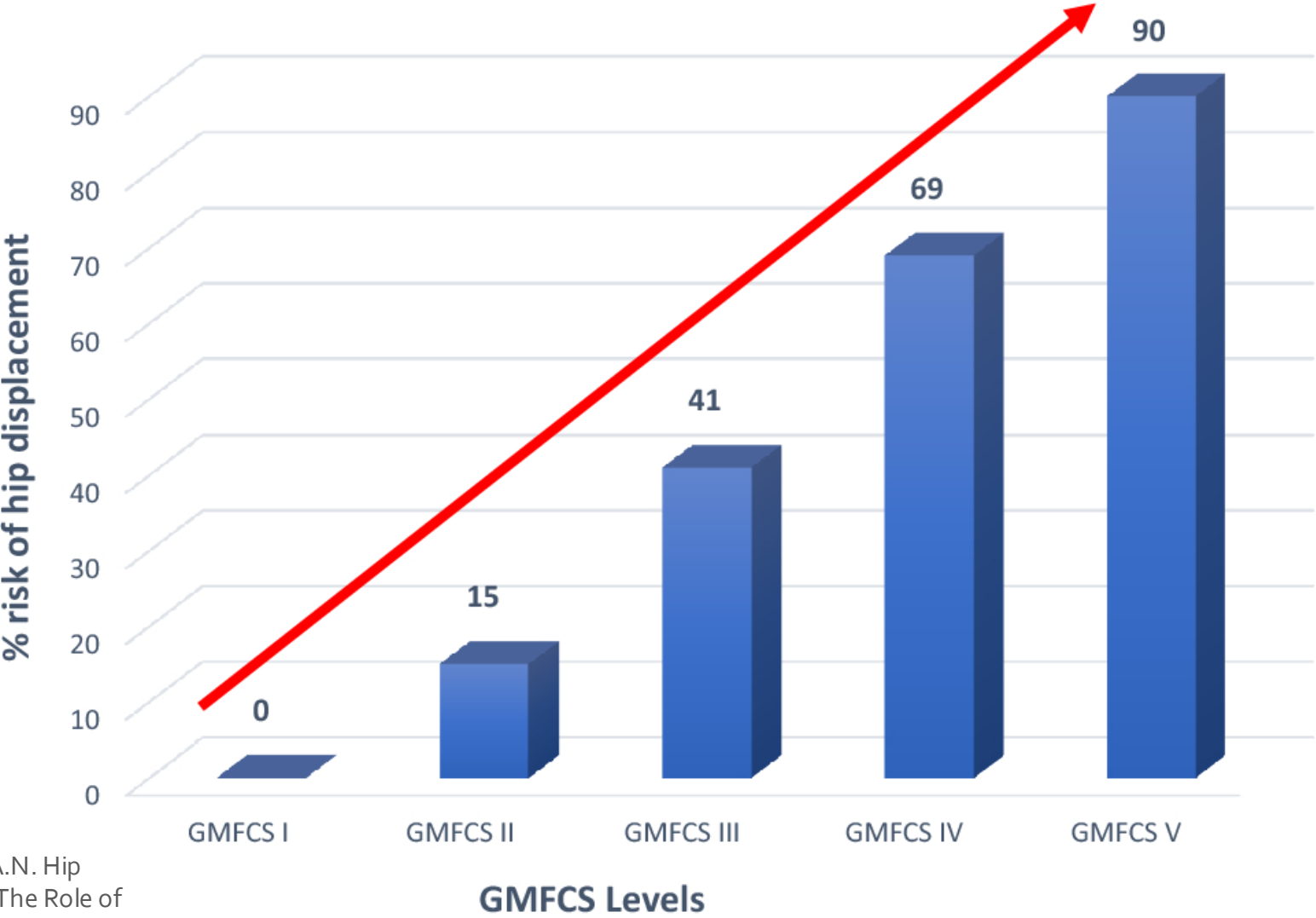
The direction of dislocation will depend on the position the person lies in as a habit

To identify key components of postural care



If the leg is falling away from the midline the hip will tend to dislocate anteriorly or forwards

Risk of Hip Displacement related to GMFCS Levels

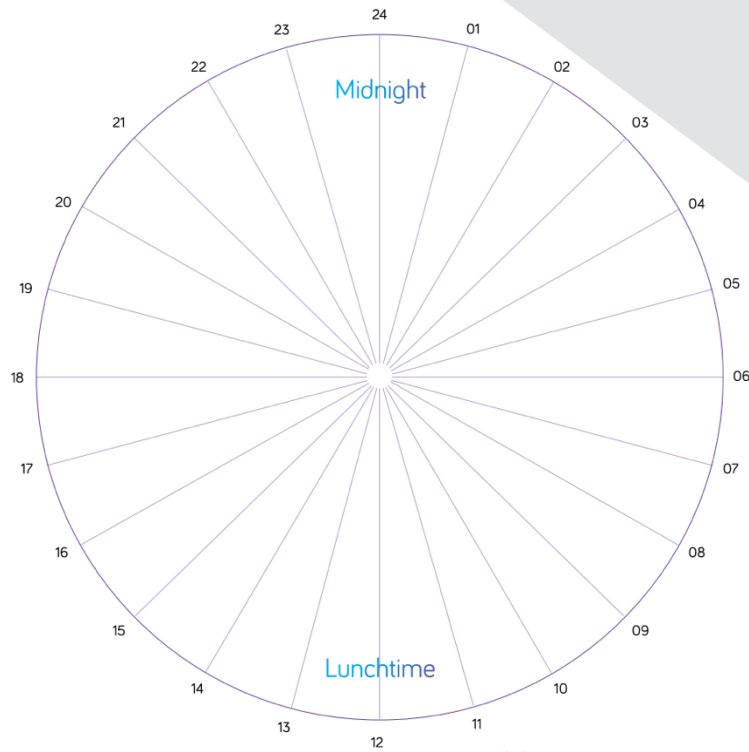


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Posture Analysis Graph

24 hour clock for: Name _____ Date ____ / ____ / ____



Instructions

- Divide the clock up according to the different positions/equipment the client is in.
- Label each sector accordingly
- Colour code each position/equipment type as per the shading key
- Calculate the percentage of the clock (24 hrs) spent in each situation
- Copy this page or email solutions@medifab.com to request more copies if required.

Shading Key

■ Bed	= ____%
■ Wheelchair	= ____%
■ Standing frame	= ____%
■ Relaxed position	= ____%
■ Other: _____	= ____%
■ Other: _____	= ____%

To suggest some practical strategies for nurses and families

Find out who your local postural care person is!
Probably a Physio or an OT...

To suggest some practical strategies for nurses and families

Then buy them cake



Take photographs

To suggest some practical strategies for nurses and families





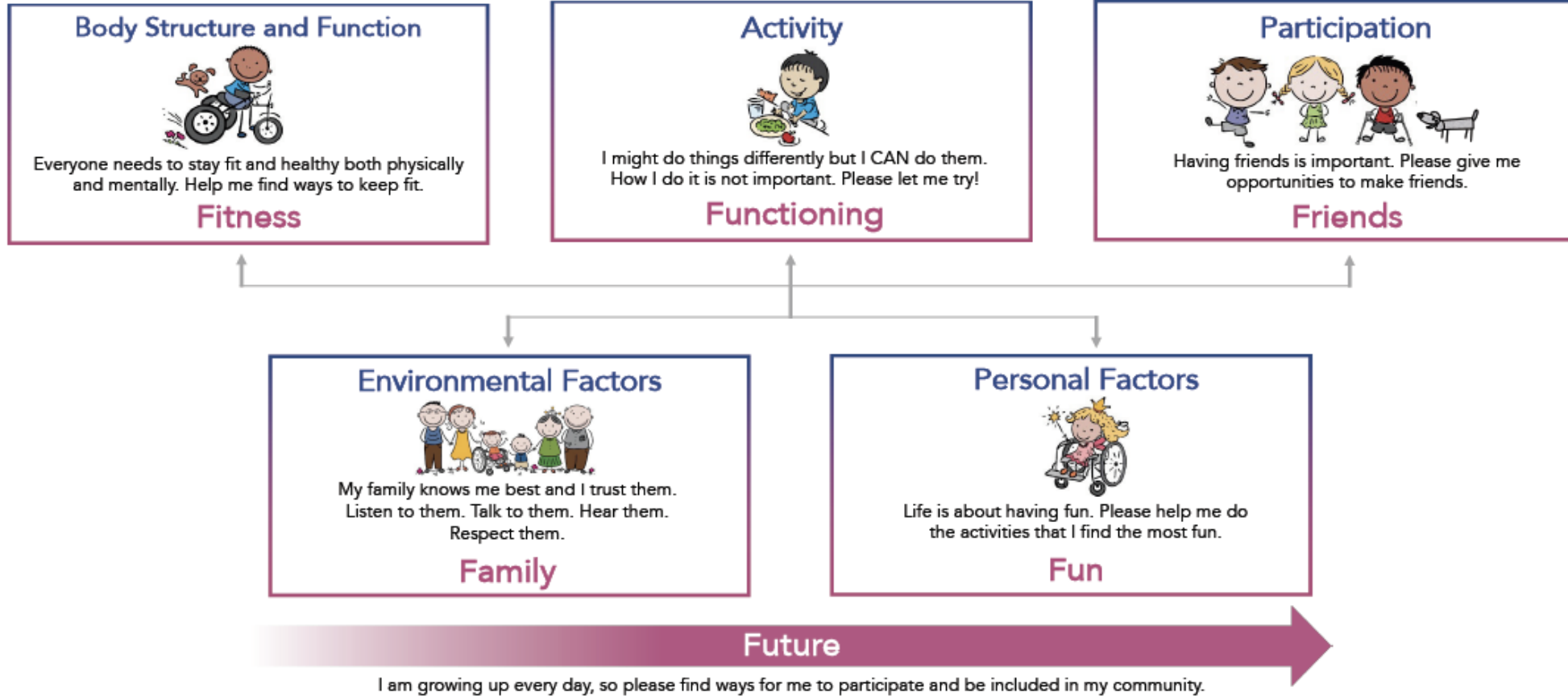
Thorough assessment in seating
AND lying is essential – check out
Sharon Sutherland at
www.postureandmobility.com

Make the link
between lying and
sitting and life in
general!!

To suggest some
practical
strategies for
nurses and
families

Simple? But the
experiences of
parents captured
by Jane Hamer
would indicate that
introducing
supported lying at
night is very
challenging
(Hamer 2025)

The ICF Framework¹ and the F-Words²



For more information visit the F-words Knowledge Hub:
www.canchild.ca/f-words



1) World Health Organization. (2001) *International Classification of Functioning, Disability and Health (ICF)*
 2) Rosenbaum P & Gorter JW. (2012). The 'F-words' in childhood disability: I swear this is how we should think! *Child Care Health Dev*; 38.

Meet Taylor



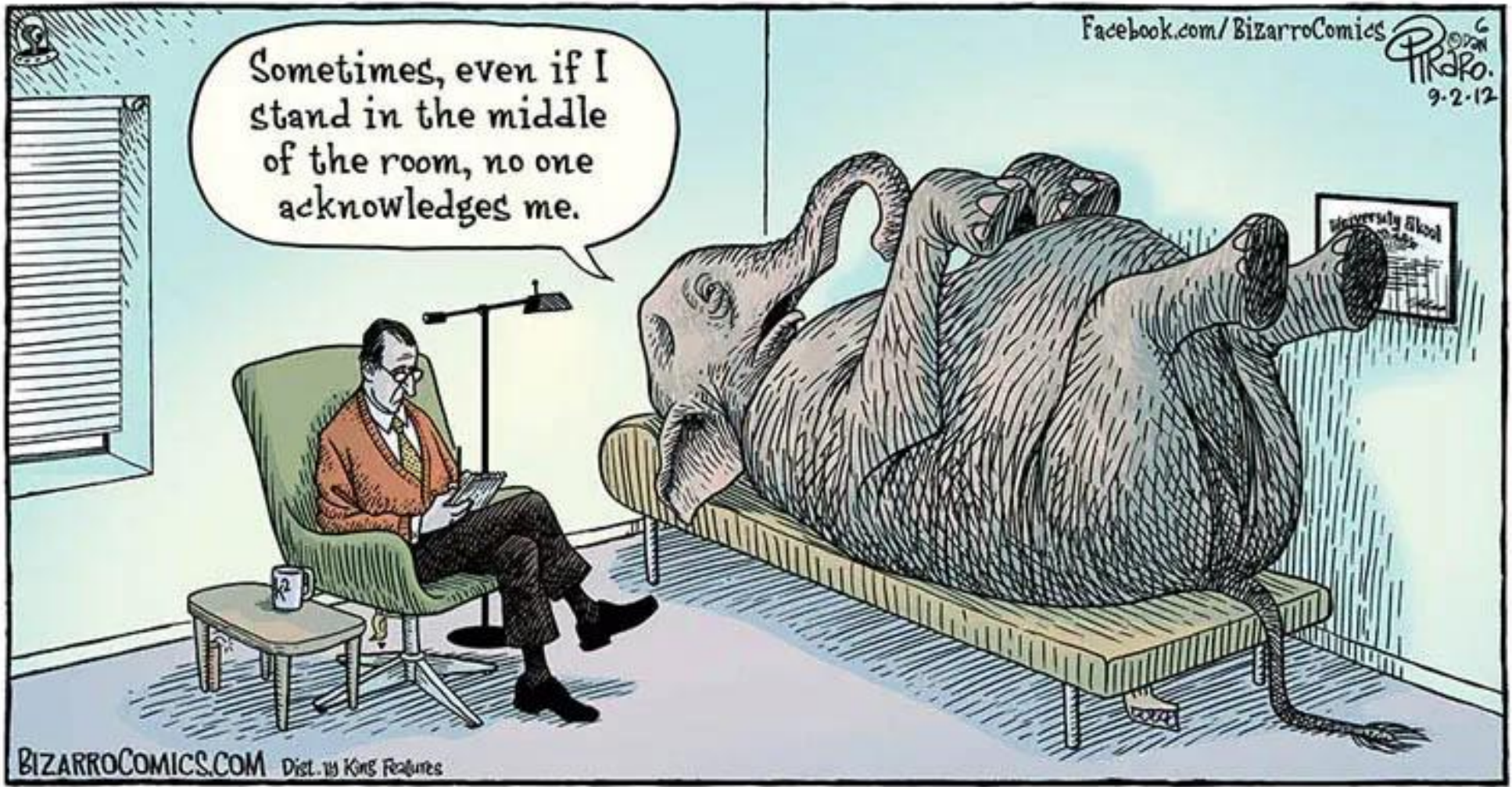
To suggest some practical strategies for nurses and families



To suggest some practical strategies for nurses and families



To suggest some practical strategies for nurses and families



To identify common challenges for those providing postural care

Person

Feels restricted
Doesn't see the point / understand the need
Moves
Finds it strange (not usual position)
Finds it uncomfortable or even painful
Finds it difficult to fall asleep
Doesn't like the look of the equipment
Tried before – bad experience / “it didn't work”
Doesn't like being told what to do
Gets too hot / sweaty
Gets in the way of my partner / parent / support worker

Service

Not enough time to assess / support / review
Not enough money for therapist contact time / equipment / training
Not what we are measuring
Difficulty in justifying preventative interventions
May save money in the future but doesn't save money today
Not aware of the evidence base
Not aware of reasonable adjustment guidelines
Misconception that gravity no longer affects people when they stop growing
Different disciplines within the MDT can be out of step with one another – e.g. response to referrals in different time scales

Medical

High muscle tone that is difficult to manage
Continence issues
Temperature control issues
Perceived conflict with other interventions e.g. PEG feeds, pressure care
Infections control issues
Risk benefit analysis incomplete

Care Giver

Not enough time
Doesn't see the point / understand the need
Doesn't “believe” in it
Too much washing
Not my job
Conflicts with something else I have been told to do
Have to keep putting the equipment in and out
Doesn't look like a normal bed
Can't remember what to do
“Why can't you just leave them alone at night?”
Interferes with my sleep and I am already exhausted

Cultural

Attitudes towards co-sleeping
No recognition that night time therapeutic positioning is required / hidden population
Misconception that night time therapeutic positioning is restrictive / unnatural / unkind
It's another trend / craze
Not a quick fix (unlike surgical intervention)
Need for postural care training not recognised

Clinical Excellence Online

Signposting to further resources and support

<p>Beverly (Billi) Cusick Physical Therapist</p> <p>Musculoskeletal issues, serial casting, orthotics, TheraTogs</p>		<p>Dr Mary Massery Physical Therapist</p> <p>Postural Control, respiratory and physiology, Complex systems</p>		<p>Susan Blum Physical Therapist</p> <p>Torticollis, asymmetries, fascial issues and TMR</p>	
<p>Dr Susan Hastings Physical Therapist</p> <p>Whole Body Vibration, eStim, Spinal Neuromodulation</p>		<p>Dawn Sandalcidi Physical Therapist</p> <p>Pediatric bowel and bladder health and function</p>		<p>Dr Pia Stampe Physical Therapist</p> <p>Treatment planning, CP, brachial plexus injuries, biofeedback</p>	
<p>Esther de Ru Physiotherapist</p> <p>Kinesiology taping, scars, scoliosis, diastasis rectus</p>		<p>Sharon Sutherland Physiotherapist</p> <p>Untangling posture and mobility (sitting, lying & standing) for function & participation</p>		<p>Sarah Clayton Postural Care Specialist</p> <p>24 Hour Postural Care Sleep Systems Body Symmetry</p>	

Search by Area of Practice

EARLY INTERVENTION | HOME HEALTH | SCHOOL BASED

Search by Age

0-18 MONTHS | AGE 1.5-3 YEARS | AGE 3-6 YEARS | AGE 6-12 YEARS

Search by Experts

BILLI CUSICK | MARY MASSERY | SUSAN HASTINGS | PIA STAMPE

Search by Diagnosis

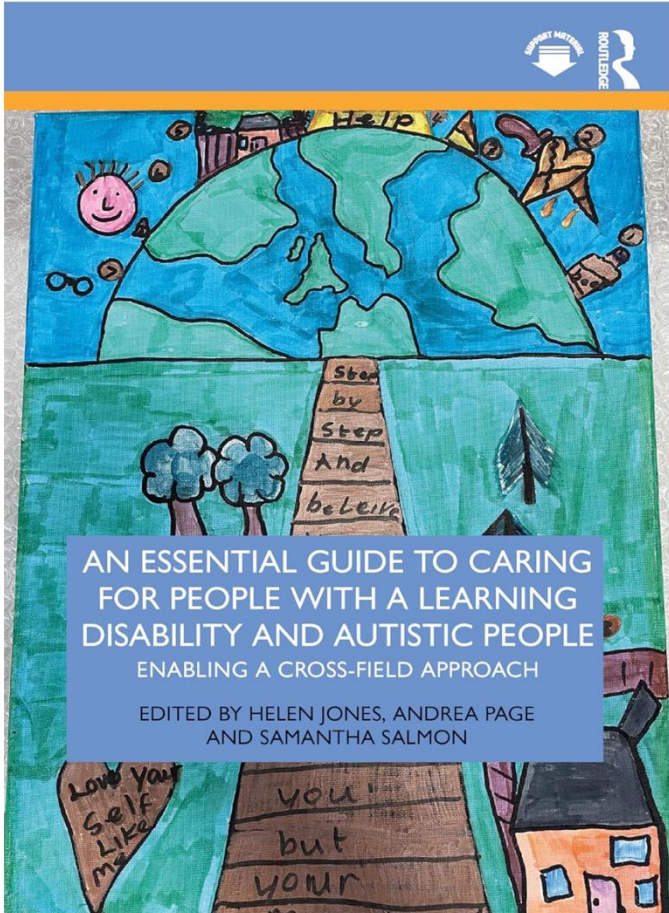
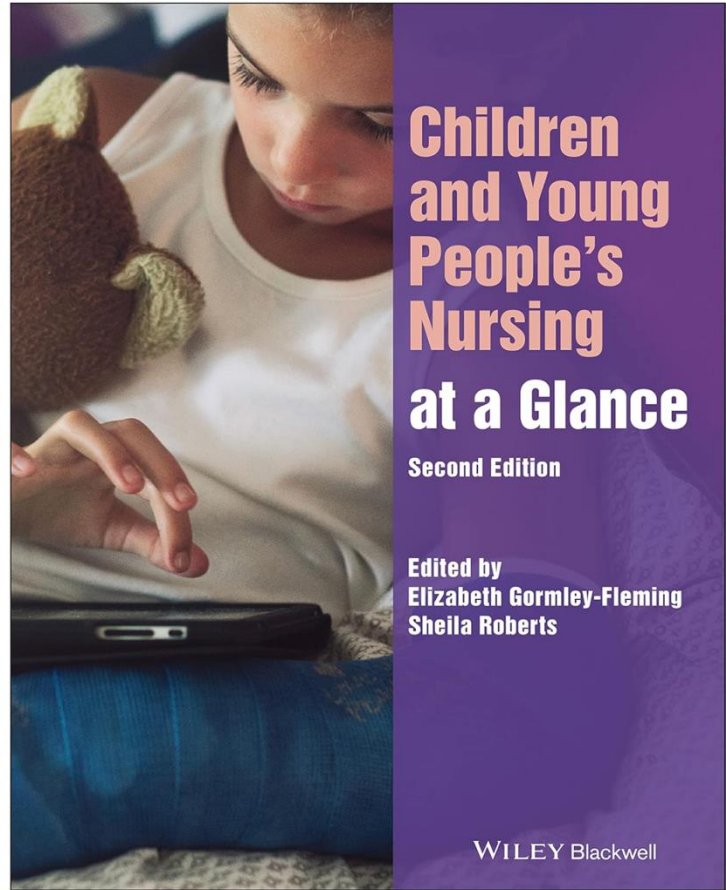
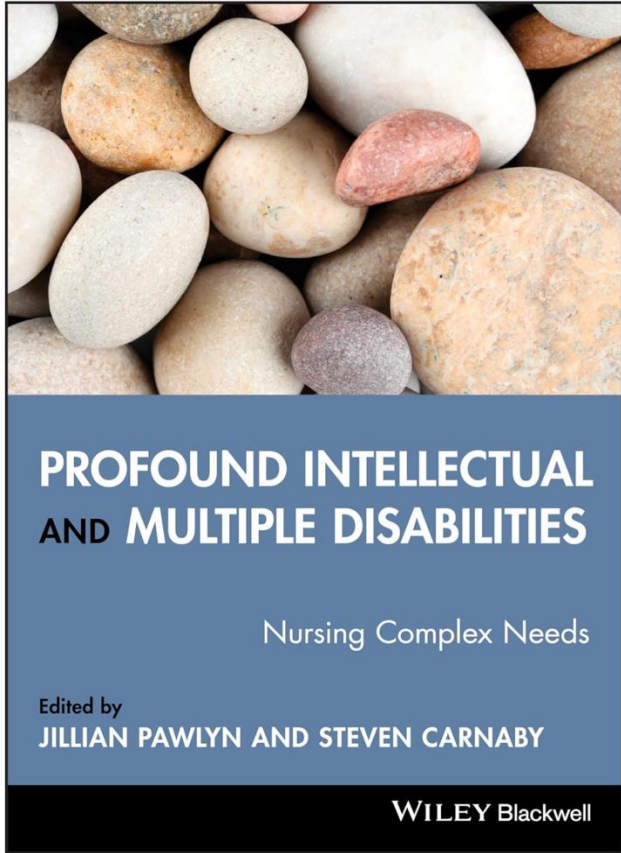
ASD | BOWEL & BLADDER | CEREBRAL PALSY | DEVELOPMENTAL DELAY

Experts	Age	Diagnosis	Area
<ul style="list-style-type: none"> Billi Cusick Mary Massery Susan Blum Susan Hastings Pia Stampe Esther de Ru Sarah Clayton 	<ul style="list-style-type: none"> 0 - 18 Months 1.5 - 3 Years 3 - 6 Years 6 - 12 Years Teens and Young Adults 	<ul style="list-style-type: none"> Cerebral Palsy Down Syndrome Developmental Delay Genetic Disorders 	<ul style="list-style-type: none"> Early Intervention School-Based Therapy Home Health

[Suggest a new category](#)

Postural Care Nursing Resources

Signposting to further resources and support



Signposting
to further
resources
and support

Further resources

- [The Skies We're Under](#) – parenting podcast for anyone who wants to know what it's really like... Not for our younger listeners!
- [Postural Care Overview Tool](#)
- [Heba app](#) used to track children's care and to share information with clinicians
- The Goldsmith Development Programme by Simple Stuff Works – contact Sarah for details
- Simple Stuff Works [YouTube channel](#)
- Simple Stuff Works [resources page](#)
- Simple Stuff Works resource booklet <https://www.simplestuffworks.com/wp-content/uploads/2024/01/Therapeutic-Lying-Handout-2024.pdf>
- ISWP webinars postural care in [less resourced settings](#)

Thank you for your time, commitment and fabulousness!!

And a personal thank you to all the paediatric nurses that have supported me and my daughter in surgical wards, neuro wards, intensive care, imaging departments, A and E, oncology wards, at home and in school – legends every single one!!

Email: Training@simplestuffworks.co.uk

Office: 01827 307870

References

- Hill (Clayton), S. and Goldsmith, J., *Biomechanics and prevention of body shape distortion*. The Tizard Learning Disability Review. 2010. Vol. 15, Issue 2, pgs. 15 – 29
- Casey J, Rosenblad A, Rodby-Bousquet E. Postural asymmetries, pain, and ability to change position of children with cerebral palsy in sitting and supine: a cross-sectional study. *Disabil Rehabil*. 2022 Jun;44(11):2363-2371. doi: 10.1080/09638288.2020.1834628. Epub 2020 Nov 3. PMID: 33142069.
- Hamer, J., Graham, F., Martin, R., Ranta, A. (2025). Caregivers' Experience of Sleep Systems for Children with Complex Neurodisability: A Qualitative Study. *Physical & Occupational Therapy in Pediatrics*, 45(3) 401-422. <https://doi.org/10.1080/01942638.2024.2419642>
- Sharon Sutherland – seating and lying assessment www.postureandmobility.com
- Listen to Jane discussing her findings here It's a complex night – <https://www.bornattherighttime.com/the-skies-we-are-under-podcast/>
- Goldsmith, L. Golding, RM. Garstang, RA. Macrae, AW. *A technique to measure windswept deformity*. *Physiotherapy*. 1992; (78) 4; 235-42. Goldsmith, J., & Goldsmith, E. (2013).
- Jo de Clercq – Sensorimotor disintegration. Connect with him via LinkedIn for updates and materials <https://www.linkedin.com/pulse/paratonia-people-dementia-jo-de-clercq/>
- Further online CPD certified training <https://www.bornattherighttime.com/24-hour-postural-care/>