



# **Pain & Palliative Care Forum**

**Webinar 29<sup>th</sup> April 2026**

# Overview



1300 – 1305 Welcome and Overview



1305 – 1320 Meet the forum steering committee



1320 – 1345 Overview of forum work + Q&A



1345 - 1430 Launch Learning Disabilities Pain Assessment Resource (LDPAR)

# Remembering Felicia (Flick) Cox

## FRCN

- Nurse Consultant Pain Management Royal Brompton and Harefield Hospital
- Past chair of Pain and Palliative Care Forum
- Fellow of The Royal College of Nursing
- Specialist interest in Acute Pain and opioid safety.
- Lived experience of cancer-related pain
- Past Editor of The British Journal of Pain
- Secretary of IASP Acute Pain SIG
- Honorary member of The British Pain Society
- Co-Chair EFIC Nursing Education Group





Royal College  
of Nursing

# Meet The Forum Steering Committee

# Forum Steering Committee

Martin Galligan Chair

Olajumoke Isaiah Vice Chair

Rachel Desai

Rachael Barton

Sharon Taylor

Kelly Moffat

Charmaine Butcher



# Forum Work

# Fundamentals of Palliative and End of Life Care

## Fundamentals of nursing care at the end of life

From: [Fundamentals of nursing care at the end of life overview](#)

📅 Last quality assured: 17/03/2026 ...

**Content** | [Links and Resources](#) | [References](#)

- ✓ Fundamentals of nursing care at the end of life
- ✓ National guidance and legislation
- ✓ Communication
- ✓ Advance care future planning
- ✓ Symptom management
- ✓ Anxiety delirium terminal agitation and distress
- ✓ Nutrition and hydration
- ✓ Ethical considerations
- ✓ Cultural and spiritual needs
- ✓ Care after death
- ✓ Self-care
- ✓ Case studies
- ✓ References



This guide will help you understand what is important when caring for a person approaching the end of their life – particularly the last year of their life. It will also help support your communication skills when discussing end of life care and enable you to navigate difficult conversations whilst maintaining compassionate patient care.

### How will this guide help me?

This learning resource is for nursing staff across all health care settings, including health care assistants, nursing associates, registered nurses and specialist nurses caring for people in the last year of life. The resource includes signposts to articles, blogs, podcasts and links to RCN resources to improve knowledge on end of life care.


This guide complements the [RCN online resources on end of life care](#). It could also be used as a tool to support learning on some of the challenges that may present when caring for patients who are dying.

Thank you to the project team

- Project Lead Olajumoke Isaiah
- Martin Galligan
- Sandra Campbell
- Suzanne Monks
- Charmaine Butcher
- Judy Le Marquand
- Tracy Wilson
- Anita Hayes



# UK Career Framework for Pain Nurses



Royal College of Nursing

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## UK career framework for pain nurses

You are here: [Royal College of Nursing](#) / [pagetestings](#) / UK Career Framework For Pain Nurses

**Pain is a complex and multidimensional phenomenon that does not discriminate and can affect anyone at any stage in their life time.**

The International Association for the Study of Pain (IASP) now define pain as "An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage," (IASP 2020). This new definition recognises that regardless of the cause of the pain it is a personal experience that if influenced by biological, psychological and social factors. Pain can be described in a variety of ways by onset and duration (procedural, acute, chronic/persistent, Cancer related), by mechanism (peripheral, central, thermal etc) or indeed if it is nociceptive, neuropathic or nociplastic. Its incidence within the UK varies across these domains.

Globally pain is the leading cause of disability with chronic pain conditions heavily featured in the top ten causes of disability (Mills, Nicolson and Smith 2019). Within a UK population this translates into up to 50% of individuals being affected by chronic pain (Fayaz et al 2016). Due to the complexity of pain it essential that the nursing workforce is equipped with the knowledge and skills to support individuals living with pain.



**Pain and Palliative Care Forum**

- > Forum homepage
- > Professional Lead contact

Advertisement

# Podcasts

- Caring for people with dementia at the end of life
- How specialist palliative care nurses respond to patient-initiated conversations related to assisted dying
- Digital Legacy
- Late Effects: Cancer-related pain
- Why normalising grief in healthcare is important
- "Sharp Scratch" - Exploring the lived experience of procedure-related pain.
- Delivering person-centred care in a palliative setting

### Pain and Palliative Care Forum Podcasts and Webinars

**Caring for people with dementia at end-of-life**

In this episode, we are joined by Cathryn Smith, Professional Lead in Adult Community Nursing and End-of-Life-Care. Cathryn shares the findings from her PhD studies, which explore the provision of palliative and end-of-life care services in the community for adults with dementia.



**How specialist palliative care nurses respond to patient-initiated conversations related to assisted dying**

In this episode, we are joined by Victoria Ali, Lead Nurse for Palliative Care at Bradford Teaching Hospital. Victoria is a PhD student at Lancaster University and discusses her doctoral work, which explores how nurses working in specialist palliative care can respond to patient-initiated conversations about assisted dying. For more information on Victoria's work you can read the [findings from her systematic review](#).

For more information regarding the RCN's work around assisted dying including the updated position statement and current state of legislation you can visit the [assisted dying webpage](#).



**Digital Legacy**

The Pain and Palliative Care and the Digital Nursing Forums Present: Digital Legacy

Presented by Sarah Stanley, RN - PhD researcher, Liverpool John Moores University and Research Nurse, Marie Curie



**Late Effects: Cancer-related pain**

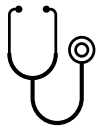
In this edition of the Pain and Palliative Care Forum podcast, we explore cancer-related pain as a consequence of cancer treatment, commonly referred to as late effects. In this episode, Martin is joined by Falcia Cox, who shares her lived experience of late effects cancer-related pain as Professor Diana Greenfield, a nurse consultant in late effects at Sheffield Teaching Hospital.

For more information regarding self-management advice regarding pain, please visit <https://painconcern.org.uk>.





Resolution access to palliative care



Matter for discussion access to pain services



Learning event fundamentals of end-of-life care



Meet the forum events



# Projects for 2026/27



Palliative care career  
framework



Opioid resource



History of Pain



Annual Conference



# RCN Pain and Palliative Care Conference Breaking Barriers: Advancing Access to Palliative and Pain Care

Tuesday 22 September 2026  
9am - 4:45pm  
RCN HQ, London

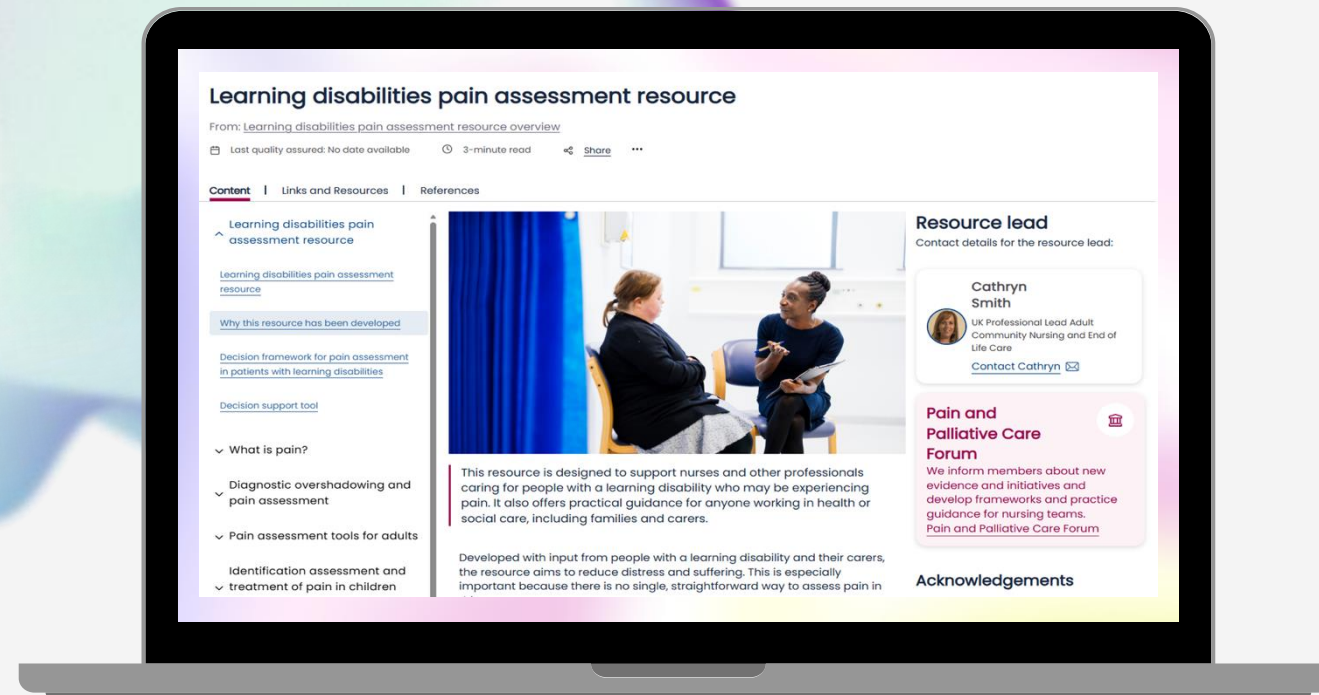




**How can the forum support  
you?**

# Pain Assessment Resource for those caring for people with a Learning Disability (LDPAR): Person – Led Approaches

A project to develop a resource for people caring for people with a Learning Disability



RCN Pain and Palliative Care Forum Webinar

Formal Launch of LDPAR (April 2026)

# Aim

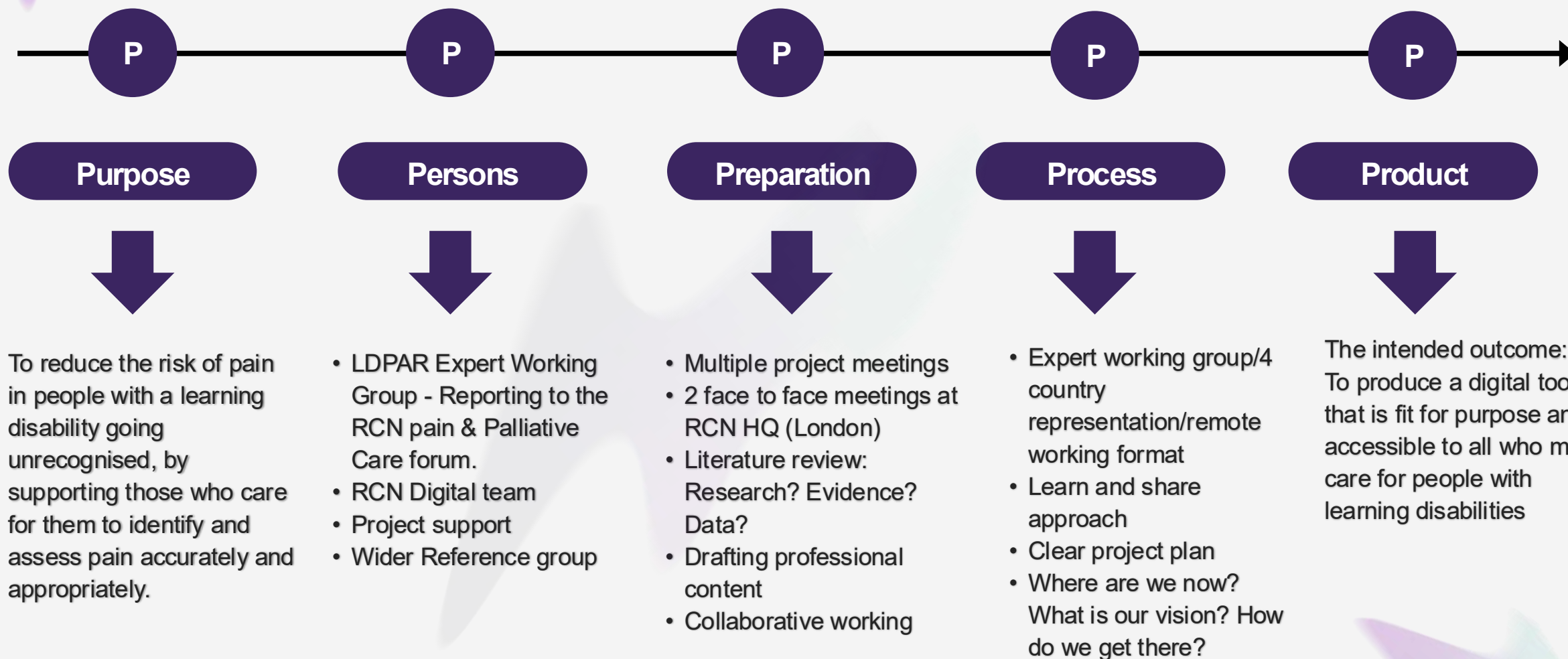


**To empower nurses and anyone caring or supporting someone with a Learning Disability with a range of tools for identifying and managing pain. This will cover a wide range of individuals from age 3 upwards with communication needs and intellectual differences.**

# Key Objectives



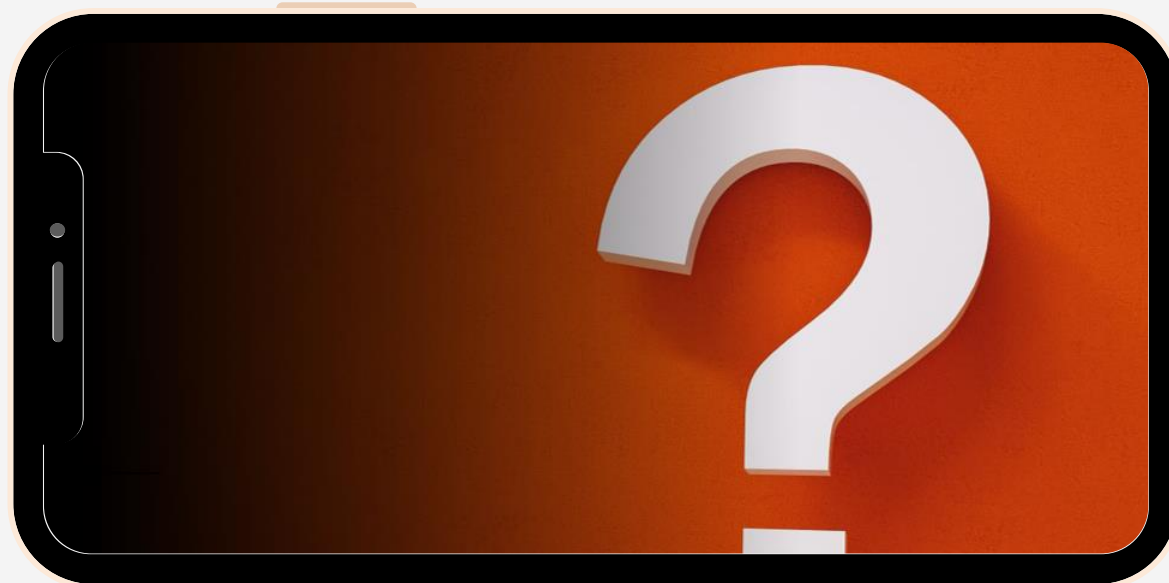
- 1. Develop a pain assessment and management of pain toolkit for people with Learning Disabilities.**
- 2. Work with teams across the 4 countries in the UK development of the toolkit to ensure the objectives are meaningful and relevant to clinical practice.**
- 3. Engage 4 working groups: one in all 4 countries with representation of people with learning disabilities and carers.**
- 4. Conduct a literature review to inform the evidence base for the project.**
- 5. Use the PDSA model of improvement.**
- 6. Include the management of pain for people who have a Learning Disability and are receiving palliative or end of life care.**
- 7. Develop a robust implementation and evaluation process to demonstrate the value and benefit of the toolkit.**



# Question

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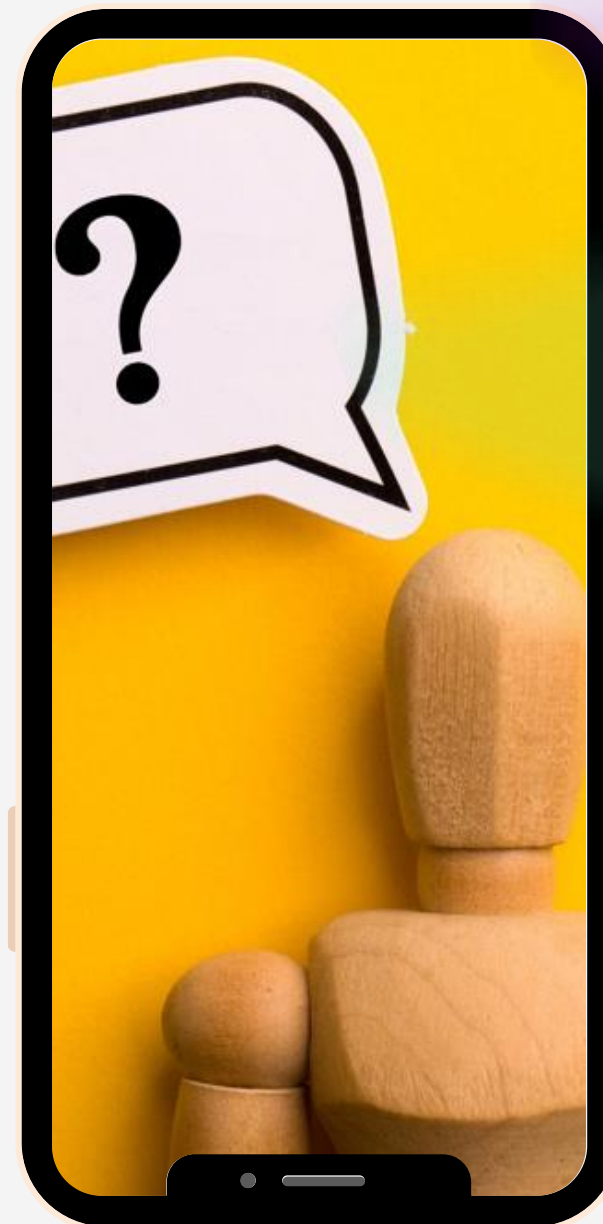
**What are the challenges of delivering person centered care for people with Learning Disabilities ?**



# Question

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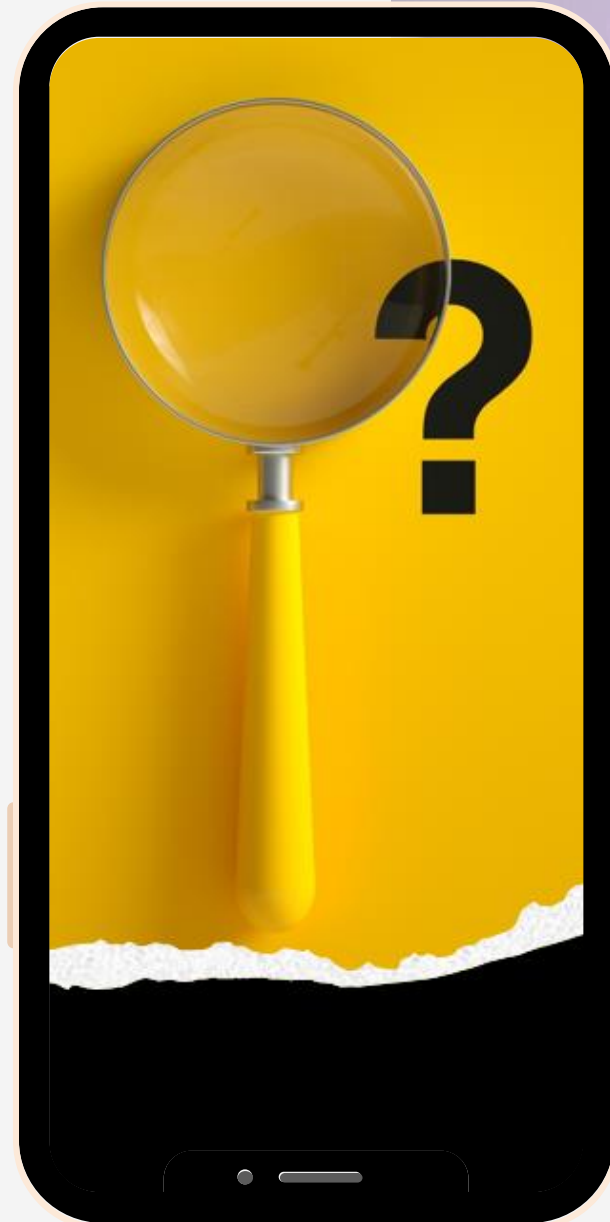
**How can we embed a person-centered approach into our practice?**



# Question

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**How can we  
demonstrate the  
evidence?**



# Question

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**What role do family members/caregivers have in delivering person centred care?**



# Key Questions for carers for consideration...

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- What makes you think your family member/ patient has pain?
- How do you know when your family member/patient has pain?
- Can you describe any behavioural changes that may indicate pain?
- Have you noticed a change in eating habits e.g., reduced appetite?
- Have you observed any change in bowel/ urinary habits?
- Is your family member /patient touching or rubbing any particular part of the body?
- Is your family member/patient more irritable than usual or crying?

— Is the person withdrawn more than usual?



# Why use a tool?

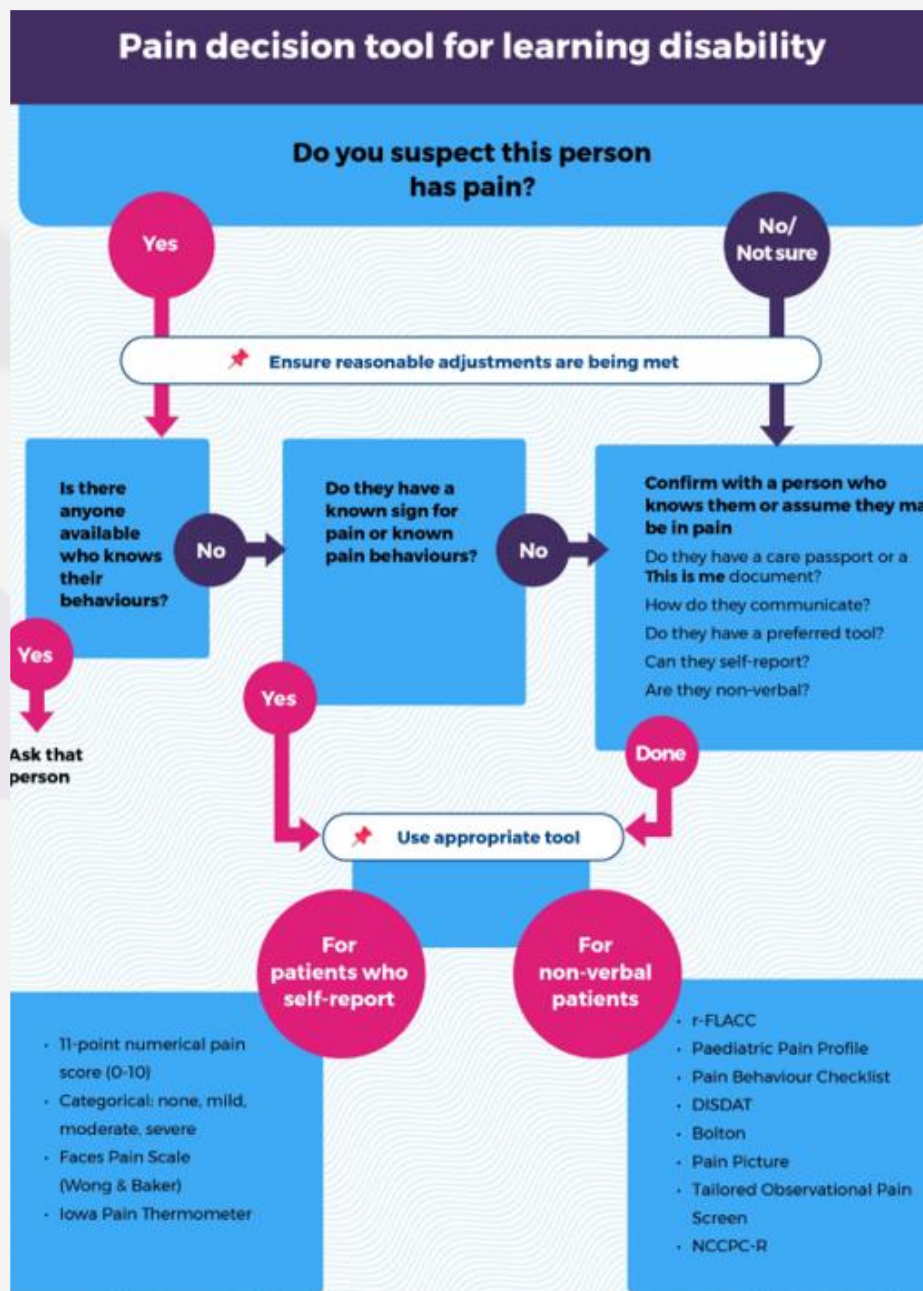


# Decision Tool

✓ The decision tool has been designed to help you identify the most appropriate assessment tool to use.

✓ This is a guide and provides advice on which assessment tools are available that capture verbal and non-verbal assessments.

✓ Acknowledgement to Felicia Cox (FRCN)



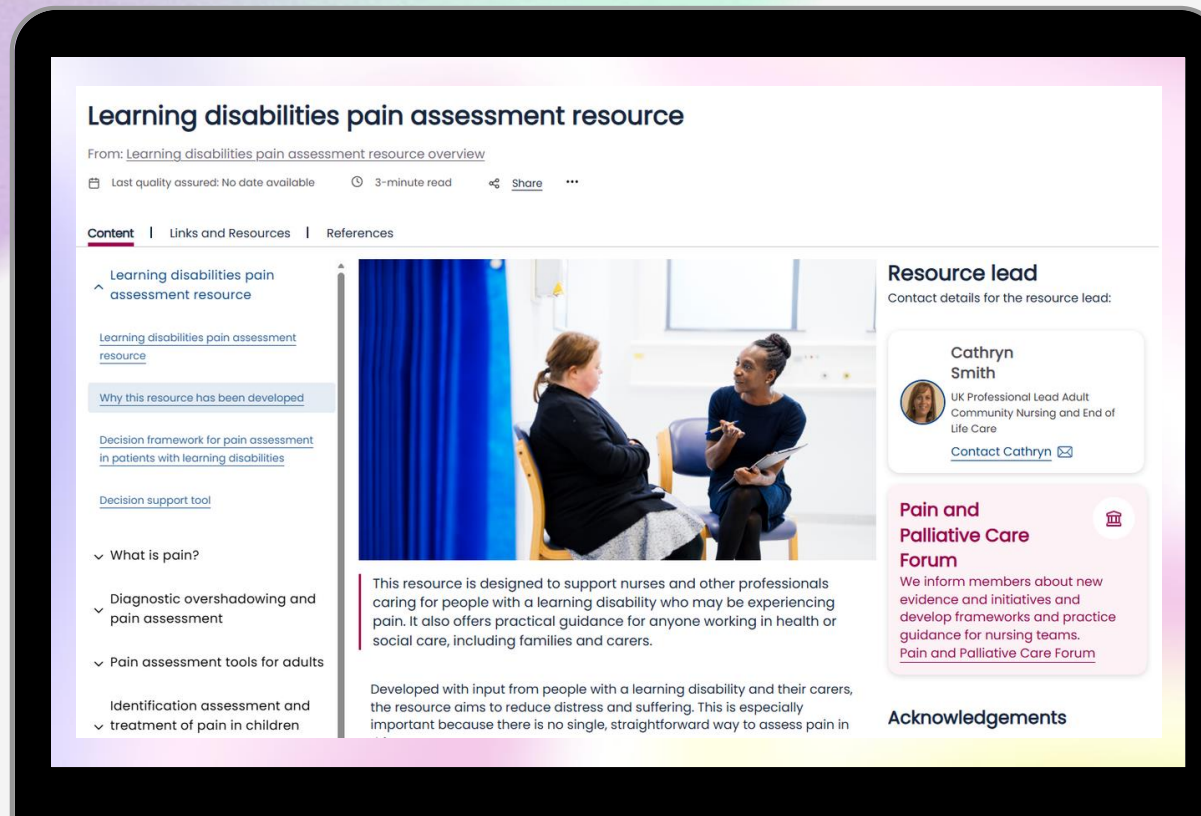
# Topic Areas

- Introduction/background/Scope
  - ❖ Why, What, Who, How? Where and When
- What is pain?
  - ❖ Pain assessment - Documentation
  - ❖ Children- adults
- Care settings
- Communication
  - ❖ Between teams and with patients and families
- Equality and diversity – threaded throughout
- Case Studies
- References
- Resources



# Pain Assessment Resource for those caring for people with a Learning Disability (LDPAR): Person – Led Approaches

[LINK TO RESOURCE](#)



The screenshot shows a webpage titled "Learning disabilities pain assessment resource". It includes a breadcrumb trail, a quality assurance notice, and a 3-minute read indicator. The page is divided into a left sidebar with a table of contents, a main content area with an image of two people talking, and a right sidebar with contact information for the resource lead and a forum link.


## Learning disabilities pain assessment resource

From: [Learning disabilities pain assessment resource overview](#)

Last quality assured: No date available | 3-minute read | [Share](#) | ...

**Content** | [Links and Resources](#) | [References](#)

- [Learning disabilities pain assessment resource](#)
- [Learning disabilities pain assessment resource](#)
- [Why this resource has been developed](#)
- [Decision framework for pain assessment in patients with learning disabilities](#)
- [Decision support tool](#)
- ✓ [What is pain?](#)
- ✓ [Diagnostic overshadowing and pain assessment](#)
- ✓ [Pain assessment tools for adults](#)
- ✓ [Identification assessment and treatment of pain in children](#)



This resource is designed to support nurses and other professionals caring for people with a learning disability who may be experiencing pain. It also offers practical guidance for anyone working in health or social care, including families and carers.

Developed with input from people with a learning disability and their carers, the resource aims to reduce distress and suffering. This is especially important because there is no single, straightforward way to assess pain in

### Resource lead

Contact details for the resource lead:

**Cathryn Smith**  
UK Professional Lead Adult Community Nursing and End of Life Care  
[Contact Cathryn](#) ✉

### Pain and Palliative Care Forum

We inform members about new evidence and initiatives and develop frameworks and practice guidance for nursing teams.  
[Pain and Palliative Care Forum](#)

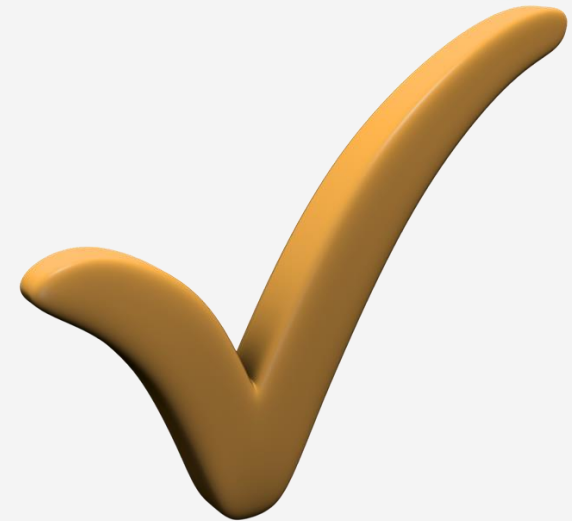
### Acknowledgements

# How do we build a quality assured education and support process?



# Next Steps

- Toolkit to be shared widely across health & social care
- Review in one year



# Acknowledgements

W

Wales

**Ruth Northway (FRCN)** – Professor Emerita of Learning Disability Nursing

I

Northern Ireland

**Maureen Roberts** – Learning Disability Consultant Nurse, Southern Health and Social Care Trust

S

Scotland

**Carol Dale** –RCN Professional Lead Independent Health & Social Care  
**Kirsteen Cowling** – Senior Staff Nurse, Children’s Hospices Across Scotland, Children’s Hospices Across Scotland  
**Sandra Campbell (FRCN)** – Independent Nurse Consultant  
**Scott Taylor** – Nurse Consultant, Learning Disabilities

E

England

**Aimee Cross** – Learning Disability Nurse  
**Anna Terry** – Team Leader, Neonatal Care; Acorns Children’s Hospice  
**Esther Smith** – Advanced Clinical Practitioner, LSCFT All-Age Learning Disability Services  
**Felicia Cox (FRCN)** – Nurse Consultant, Pain Management Services – Nursing Research Lead  
**Karin Cannons** – Nurse Consultant and Service Lead – Pain Management  
**Martin Galligan** – Lecturer Practitioner, Programme Lead MSC Advanced Clinical Practice in Cancer Care  
**Rachel Desai** – Nurse Consultant, Pain Team, Birmingham Children’s Hospital  
**Sarah Sherwood** – Quality Improvement Lead Nurse  
**Serena Jones** – Acute Liaison Specialist Nurse, Learning Disabilities and Autism  
University hospitals of Liverpool group  
**Vicky Sandy-Davis** –RCN Professional Lead Care Homes

# Special Thanks

- Additional thanks to the wider reference group**
- Special thanks to Felicia Cox and Karin Cannons for their advice and development of the decision tree.**

# Remembering Flick



This tool is dedicated to the memory of Felicia Cox (Flick), whose insight and compassion inspired its creation. As a founding member of this project, Felicia recognised the vital need for a meaningful way to assess pain in people with learning disabilities. Her vision shaped the foundation of this work, and her contribution continues to guide it. Though she sadly died before its launch, her legacy lives on in every life this resource will support.

We remember her with gratitude and love.



