Pressure Ulcer Prevention at Home

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Pressure Ulcer Prevention At Home 1 Study (PUP@Home1)

Summary of Findings

Research was undertaken to understand what resources (interventions) people need to prevent pressure ulcers at home.

The research included:

- People with Long-Term Neurological Conditions (LTNCs), who live at home.
- Their informal carers (for example, family members).
- Their Personal Assistants (PAs: a type of paid carer).
- Healthcare Professionals and organisations providing support related to LTNCs.

Pressure ulcers (PUs) sometimes called bedsores or pressure sores, are damaged skin and tissue caused by lying or sitting in one position for too long. We have focused on people with LTNCs that make it harder to move, for example, Multiple Sclerosis, Spina Bifida and Spinal Cord Injury, as they can be at high risk of PUs.

This was a user-led (participatory) study, which means that people with real life experience of PU risk were doing the research. We explored how to make PU prevention part of wider self-care and how informal carers and PAs support PU prevention. The study was split into 4 stages:

1. We set up two research groups, one with people with LTNCs and informal carers, and one with PAs.
2. Following training, research group members interviewed others with LTNCs and carers. Information was also collected via a smartphone app.
3. A workshop was held with professionals (for example, nurses, physiotherapists, NHS managers and charity staff).
4. People from stages 1 and 3 came together to share their work and map what helps or hinders PU prevention.

Thank you for your contributions to the research. Here is what we found:

Overall, 74 participants including 31 service users, 8 carers, 9 PAs and 26 professional / strategic stakeholders took part in the study.

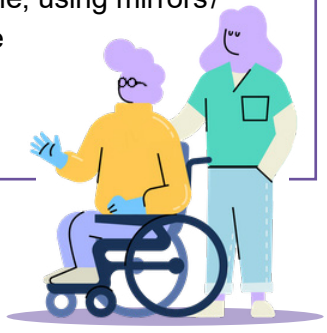
We identified 8 themes:

1 Learning

- Many people with LTNCs did not receive or remember receiving information about PU risk with some only becoming aware of their risk through this study. They recognised the need for raising awareness.
- Other people with LTNCs were very aware of their risk and had made PU prevention a priority in their lives. They noted the need for more information and support about when and how to seek help if they spotted signs of pressure damage.
- People wanted resources about how to prevent PUs (and how to adapt as things change).
- Carers and PAs mentioned the lack of opportunities to learn about PUs and prevention. Many PAs did not see this as part of their role and were unsure of what action to take if they noticed skin damage.

2 Safe routines

- People with LTNCs have routines for caring for themselves, balancing many needs and risks, sometimes across multiple conditions. For many, preventing PUs was just one small part of a very complicated picture.
- Many people developed ‘safe routines’ to help them live PU free for example, using mirrors / cameras to view hard to see areas and setting alarms to prompt position changes.



PUP@Home1 Article: https://www.sciencedirect.com/science/article/pii/S0965206X24001311?via%3Dihub

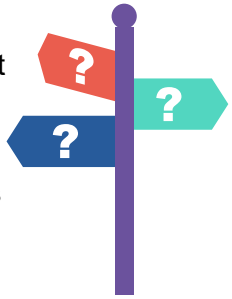
3 Third sector and peer support

Third sector is a term used to describe the range of organisations that are neither public sector nor private sector such as voluntary and community organisations, charities, or self-help groups. Peer support can be described as when people with similar experiences offer assistance to each other.

- People with LTNCs, their carers and PAS really valued the resources and support on offer from third sector organisations (for example, condition related charities).
- Peer support was valued, including trained support workers, social media and friends.
- Some people used services outside of the NHS because of a lack of clear information on which support to access, long waits and a desire to reduce the burden on NHS services.

4 Navigating complex systems

- Many with LTNCs stated the high mental load and stress from dealing with their conditions and the complexity of managing services, finances, recruiting and training PAs.
- People referred to multiple appointments with limited communication between health/social care teams.
- Some built up knowledge of their local services and what to say to be taken seriously by professionals. Others did not feel listened to or felt blamed for getting a PU.
- People with LTNCs found it difficult to advocate for their own needs, particularly if feeling unwell.
- Carers and PAs said they acted as advocates which they stated is a vital but difficult role.



5 Adapting and reacting to change

- People described 'danger points' where their risk levels changed or where self-care became more challenging, like life events or temporary changes (for example, job changes, holidays, illness).
- Some healthcare professionals felt their roles were not flexible enough to support these changes. PAs said they were able to adapt to these changing needs but are not always involved in wider meetings about their client's care needs.

6 Perceptions of risk

- People's perceptions of their PU risk changed over time. It can be difficult to think about risks that might happen in the future.
- People with LTNCs and carers said they felt shame and guilt for getting a PU because they thought this meant the care for themselves or for a family member wasn't good enough.
- People who had experienced a PU said this had made them take extra notice of changes and were more focussed on preventing it happening again.

7 Risk negotiation

- At times, there were differences between what people with LTNCs and professionals thought was a risk and what level of risk was acceptable. This made conversations about risk challenging.
- People needed flexible prevention strategies, which fit with their existing self-care routines and lives.

8 Supporting roles

- Family members provided vital prevention support.
- Positive and negative impacts on family dynamics were discussed. Some preferred to keep family members separate from their care, carers felt guilt if that person developed a PU.

What are we going to do with these findings? Next steps

We are currently undertaking a follow-on project to develop and test resources to support PU prevention at home for people with LTNCs, carers, PAs and healthcare professionals.

https://fundingawards.nihr.ac.uk/award/NIHR163165 or contact the study team at PUPstudy@leeds.ac.uk or 0113 343 0282.

Thank you *to our Co-operative Inquiry Group members including people living with LTNCs, carers and PAs, all of our research participants, members of the Pressure Ulcer Research Service User Network UK past and present, our Project Coordination Group, Steering Committee and funder who made this study possible.*

FUNDED BY

NIHR | National Institute for Health and Care Research

This study is funded by the NIHR Health and Social Care Delivery Research (HSDR) Programme (Award ID: NIHR134029). The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.