



Carer's Network Bulletin

July 2024

The aim of this current awareness bulletin is to provide a digest of recent guidelines, reports, research and best practice.

General resources
Healthtalk.org Real people. Real life experiences. Thousands of people have shared their experiences of health on film to help you understand what it's really like, from people who've been there.
Lincolnshire Recovery College The Lincolnshire Recovery College offer free educational courses about mental health, recovery and wellbeing. Courses are open to anyone aged 16+ who lives, works or studies in Lincolnshire. There is no referral needed, they can choose the sessions that they would like to come to and register using the online form. See courses available here.

1000 voices not 1

Cancer disparities in diagnosis and care exist between people from different backgrounds in the UK. [Cancer Equals is a campaign launched by Bristol Myers Squibb](#), to understand and help address the many factors that lead to delays in cancer diagnosis and variations in cancer experiences between people from different backgrounds. Cancer Equals research shows that people from minority ethnic groups experience seven months longer delays between noticing cancer symptoms and diagnosis compared to white individuals. Many factors lead to these delays in diagnosis and differences in people's experience of cancer – no one's story is the same.

Adverse childhood experiences (ACEs) and engagement with healthcare services

Adverse childhood experiences (ACEs) are associated with poorer health outcomes yet their association with healthcare engagement remains relatively underexplored, particularly within the UK. This report from [WHO Collaborating Centre on Investment for Health & Wellbeing](#) presents the findings of an online survey with adults resident in Wales and England, developed to explore the association between ACEs and healthcare engagement, including comfort in the use of healthcare services.

BGS report finds lack of rehabilitation hinders older people's recovery from illness

[Reablement, Rehabilitation, Recovery: Everyone's Business from the British Geriatrics Society](#) focuses on rehabilitation for older people experiencing frailty or loss of function because of acute illness or exacerbation of a chronic health condition. It highlights variation in the provision of rehabilitation for older people across the UK due to a lack of services, restrictive access criteria, and limited availability of staff,



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equipment and space. This is despite evidence that older people, and the NHS, will experience significant benefits from reablement and rehabilitation.

Building on Covid-19: what next for community-centred approaches to health?

Community champions played an essential role during the Covid-19 pandemic. This [blog from the King's Fund](#) looks at how health and care leaders can ensure that community champions' contributions and expertise are maintained for the future. The Kings Fund produced Commissioning community champions: lessons from a pandemic

Commissioning community champions: lessons from a pandemic

Community champions are typically members of the community who volunteer to promote health and wellbeing or improve conditions in their local community. This [report from the King's Fund](#) found that the community champion approach is one of many community-led approaches to improving health and wellbeing.

Dying in the Margins

This [4 year research project \(2019-2023\), supported by Marie Curie and funded by the Economic and Social Research Council, part of UKRI](#), aimed to examine people's experiences of home dying in a context of financial hardship and deprivation in the UK. There is consistent evidence that most people would prefer to die at home and that this is seen as a cultural marker of a 'good death'. Whilst there has been recent success in some countries, including the UK, in reducing hospital deaths and increasing deaths at home, these gains have not benefited everyone.

Evaluation of Carers Matter Norfolk

This [report from the Institute of Public Care is an evaluation of Norfolk County Council's model of support for unpaid carers](#). It found many positive aspects of the support that were highly valued by carers and enhanced their wellbeing, and makes recommendations on scope for further improvements. It did not find evidence that the service can offer substantial savings by preventing carer breakdown, and challenges the assumptions that underpinned these expectations.

Falling through the gaps? A closer look at NHS Continuing Healthcare

NHS Continuing Healthcare (CHC) is care funded by the NHS, but provided outside of hospital for people with significant ongoing care needs. Ahead of our further work on the subject, [the Nuffield Trust explains](#) how eligibility for CHC is decided, what the data tells us about eligibility and access over time, and what the impact on individuals, carers and families can be.



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Forgotten generation: shaping better services for children and young people

This [report, based on NHS Providers' survey of trust leaders during April and May 2024](#), explores the issues in providing children and young people's services, and how trusts are working to address those issues.

Friends and Family Test

The [Friends and Family Test \(FFT\)](#) is an important feedback tool that supports the fundamental principle that people who use NHS services should have the opportunity to provide feedback on their experience. Listening to the views of patients and staff helps identify what is working well, what can be improved and how.

How to find trusted health information on social media

The [Patient Information Forum \(PIF\) has published a new public-facing poster](#) to help everyone find trusted health information online. The poster includes top tips and questions to ask before sharing information online.

iSupport for South Asian Dementia Carers

iSupport is an online, self-directed, educational programme for people looking after someone with dementia. iSupport was originally developed by The World Health Organization. [UCL Psychology and Language Sciences have adapted iSupport](#) for use by South Asian carers, and it is available in English, Bengali, Punjabi and Urdu.

Listen Up! Your Rights training

[Groundswell have created three training resources](#) to help people understand their rights and give them the confidence to speak up about them. We draw on real-life experiences of homelessness and health inequalities.

Love, care and hard work: life as an unpaid carer

Jo Vigor speaks to Karen and Yvette, a couple who beautifully demonstrate the varied and essential role that unpaid care work plays in many relationships. As they share their story we learn what support they currently receive, and what could make a positive difference. Later in the episode, Jo is joined by Deborah Fenney to talk about our recent research in this area. [Listen to the podcast here](#).

New video guides will help autistic people understand health and social care appointments

Autistic people can now get a better understanding of what to expect from screening appointments and other common NHS experiences thanks to an innovative series of videos [created and produced by Autism Bedfordshire and funded by Bedfordshire, Luton and Milton Keynes Integrated Care Board](#).



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NHS announces 143 hospitals to roll out 'Martha's Rule' in next step in major patient safety initiative

The [NHS has announced the 143 hospital sites that will test and roll out Martha's Rule in its first year](#). Confirmation of the first sites to test implementation of Martha's Rule is the next step in a major patient safety initiative, following the announcement in February of NHS England funding for this financial year.

Our vision for improving patient experience of diagnosis

The process of getting a diagnosis is becoming increasingly challenging, with February 2024 statistics showing that the proportion of patients waiting six weeks or more for diagnostic tests is 20.8%. [This report from National Voices](#) (a coalition of 200 health and social care charities in England) sets out nine key recommendations they believe will significantly improve people's experiences of diagnosis, and of health and care more widely.

Reading Well for Dementia

[Reading Well for Dementia](#) recommends helpful reading and digital resources for people living with dementia. There are also books for family, friends and carers.

Social care in a nutshell

Unlike NHS services, social care is not free at the point of use. This [resource from the King's Fund shows](#) who is eligible for publicly funded social care, how many people have requested support, and how many people's needs are not being met.

The Untold Patient Stories: Shedding light on the realities of life with a long-term condition

In [The Untold Patient Stories: Shedding light on the realities of life with a long-term condition webinar](#) the Patient's Association heard from four people who live with long-term health conditions what their day-to-day lives are like.

United against health inequalities: moving in the right direction

This [report from NHS Providers](#) shares the results of a recent NHS Providers member survey, providing an update on the progress members have made in tackling health inequalities in the past three years.

Using plain language in health information – a quick guide

A [quick guide from the Patient Information Forum](#) to using plain language in health information, including top tips, tools and data to help you make the case for health-literacy friendly materials.

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