



Long Covid Nurse Group Meeting SUMMARY

'Community Rehabilitation Alliance Standards'

Thursday 23 November 2023
1pm - 2.30pm, via Zoom



1. Welcome and Introductions

Helen Donovan, QN, Long Covid Programme Lead, The QNI, @HelenDon_RN

- Welcome everyone to this meeting.
- According to Office for National Statistics (ONS): an estimated 2.0 million people living in private households in the UK - 3.1% of the population - are living with Long Covid.
- The Long Covid Nurse Group (LCNG) is a community of practice for nurses in the community to improve care and increase understanding about the physical, mental and emotional effects of Long Covid.
- The network was created in 2021 and offers an online network of nursing colleagues; bimonthly meetings with expert speakers; regular newsletters; dedicated pages on the QNI website; Long Covid resources.
- Please get in touch if you would like to write a blog for us about either your struggles with Long Covid and/or management options, email me at helen.donovan@qni.org.uk
- To find out more or join the network, go to:
<https://qni.org.uk/nursing-in-the-community/long-covid-nurse-group/>
or scan the QR code right:



1. Community Rehabilitation Best Practice Standards

Pip White BSc MSC MA(Law) MCSP, Chartered Physiotherapist, @pipwhitept

- Chartered physiotherapist since 1991
- What I want to do is introduce you to Community Rehab best practice, it's wider than Long Covid, but Long Covid is a condition that may be managed in the community
- The Community Rehabilitation Alliance was created in 2019 as a response to the NGS Long Term Plan, it's made up of more than 55 charities and professional bodies, sister alliances in all devolved nations.
- There are two main priorities 1. Political commitment to accessing universal rehab 2. transforming how services are delivered - we have big ambitions
- Our shared ambition: 'For illness which cannot be prevented to be treated where possible in community and primary care'; 'Breaking down traditional barriers between care institutions, teams and funding streams so as to support the increasing number of people with long-term health conditions'; 'People will get more control over their own health and more personalised care when they need it'. All these quotes are from the Long Term plan.
- We've had several achievements in the last 3 years: we reported on best data practice of data collection; we identified the wide inequalities in rehab and produced 'Easing the Pain' . We're raising the profile of the need of high quality rehabilitation.
- We're working very hard with NHSE to get rehabilitation a voice in the agenda.



1. Community Rehabilitation Best Practice Standards

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- Some of the challenges we're facing include: traditional models of rehab and workforce have been configured around a single diagnosis: in the modern world that's no longer relevant, once you reach over 70, chances are you have one or two conditions and the older you get the more multi



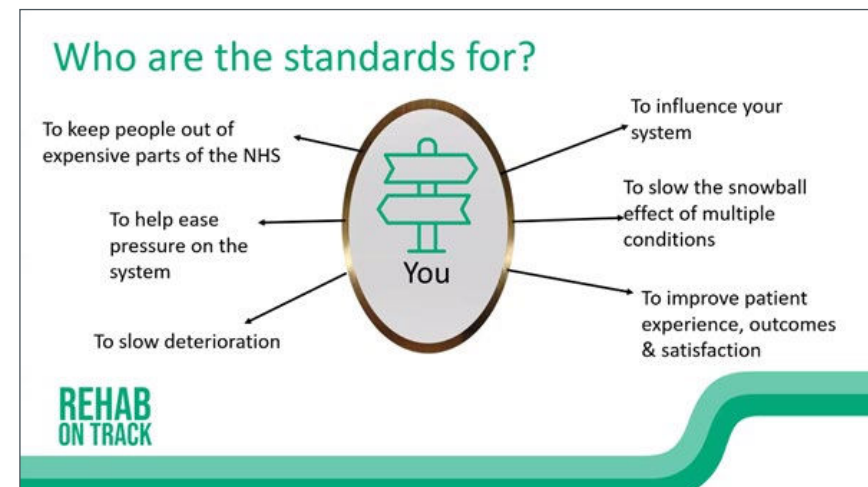
morbidity you get.

- What good rehab looks like, see left:
- Community rehab is all rehab delivered to a patient in any setting outside a hospital, by social services and any rehab in community hospitals or care homes - basically out of hospital care.
- We take on a person-centred, needs-led approach
- These are multi-professional standards, they were funded by chartered physiotherapist organisation but they're not just for physios, they're for everyone.
- We believe that rehab can only be a team effort, therefore the standards need to be designed that way.

1. Community Rehabilitation Best Practice Standards

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- If you wanted to bring this information back to ICBs: there are 4 recommendations that systems need to look at:
 1. appoint a rehab director/leader at executive level
 2. establish a local provider rehabilitation network to include all key players
 3. review existing rehabilitation services to remove silos of care and duplication of services
 4. publish an annual report on rehabilitation
- We want systems to make sure they're multi-disciplinary.
- There are 7 standards and they go across 6 domains, you could look at these standards through any lens that you want to.
- Here's the link: <https://www.csp.org.uk/professional-clinical/improvement-innovation/community-rehabilitation-recovery/important-reading/standards>
- They're for adults, anywhere in their lifespan.
- The standards come with audit tools that can be used by clinicians or directors or with patients if you want to collect feedback.
- We hope they will have multiple benefits: you can use them to influence, choose them to improve the patient experience and outcomes or ease pressure on a system.



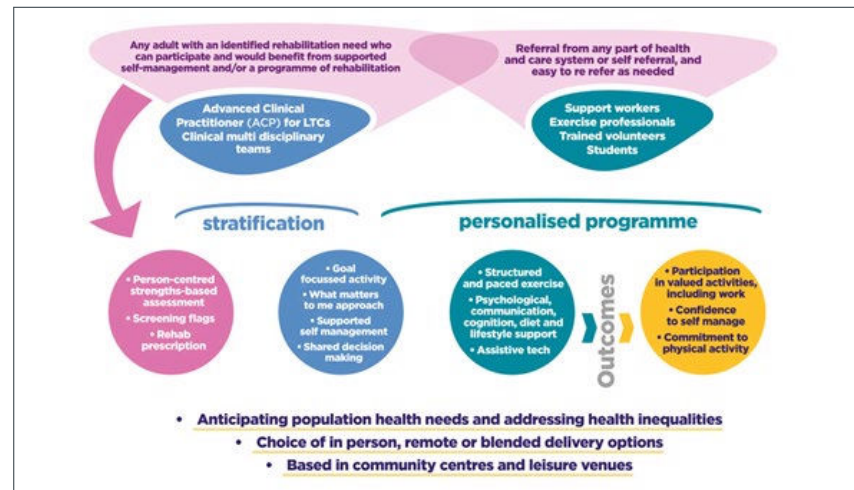
1. Community Rehabilitation Best Practice Standards

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- We're hoping they can lead to a clear pathway for people to follow - a goal of rehab is that people can maximise the life they want to live with the maximum independence for as long as they can.
- Huge numbers of skilled professionals that don't have a registrant qualification but are key to delivering rehab - the model is based on stratifying those patients that need specialised multi-disciplinary care.

How you can use the standards.

1. Pilot the audit tools
2. Pick 'n' mix approach
3. Tasting menu approach – do a bit
4. Appetizer approach – get people talking
5. Safari supper approach - Promote collaboration – network the networks
6. Online shop approach – identify issues with provision
7. Food critic approach – evaluation what rehab needs are




- We hope you look at the standards and find that they're relevant to the work you do in Long Covid services.
- Scan the QR code left to see the standards.

2. Bath Centre for Fatigue Services


Dr Anne Johnson, Associate Professor, University of the West of England, Bristol, @DrAnneJohnsonOT

- The Centre is a national service established in 2004 following a successful bid to Dept of health and later to Macmillan Cancer Support and NHSE.
- It's for people with complex fatigue including PVFS ME/CFS, cancer related fatigue and fatigue linked to other long term conditions
- Evidence-based tailored assessment and interventions
- Delivered in a closed group or tailored to a 1:1 setting (can be online or face to face)
- Stratified or personalised care is key to everything we do, in 22 years we've been running, we've only had 4 complaints from patients.
- Our team comprises consultant occupational therapists and assistant psychologists

Personalised/Stratified Care Model can be useful to assist with assessment and management of complex fatigue i.e. physical, cognitive and emotional +/-:



- 1 (Least professional input) People for whom fatigue sometimes affects their daily life a self-care approach may be adopted.
- 2 (More input than Level1) People for whom fatigue often affects their daily life a shared care approach may be useful: Bath Centre for Fatigue Services, 6 week out patient programme
- 3 (Most input) For those severely affected or have complex needs.






2. Bath Centre for Fatigue Services

Dr Anne Johnson, Associate Professor, University of the West of England, Bristol, @DrAnneJohnsonOT

- My aim is that I want patients to feel more in control again empowered and increasing in confidence by accessing what we do.
- There's a stigma around not being able to see fatigue.
- We provide evidence-based and informed interventions for fatigue and life style management which includes education for patients and their families in fatigue management strategies including: promotion of physical activity; psychosocial interventions; employment interventions and signposting.
- Supported self-management: concept of comparing yourself to a mobile phone and its charge, see slide right.
- We help raise awareness of all the things the patient does, getting kids breakfast for example will take a big chunk out of their 'battery', we can then introduce that concept of prioritising, planning and pacing
- How we helped during Covid: we created an internal helpline and people used it, our strengths lay in the knowledge and transference of our skills.
- We received 177 referrals from July 2020 to October 2022



Supported Self Management

Example

Raising awareness using the metaphor of the mobile phone:

- Plug in at night = charge 100% by morning.
- Not so with complex fatigue!
- Need to work out amount of charge: your X Factor if you like
- Everything you do will drain your battery/X Factor
- Need to work out what your X Factor is explore usage => control

Can then introduce prioritising, planning and pacing

The RUH, where you matter

2. Bath Centre for Fatigue Services

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- We still have significant amounts of data to analyse and explore
- There's a trend in people coming in for confirmation of diagnosis of ME/CFS where Covid is mentioned - we are monitoring these referrals.

- Patient feedback: *'Thank you so much for all your help in the Long Covid Zoom sessions in June. You were all very friendly and understanding and helped me to learn how to better accept and manage my illness as well have more hope for the future! Keep doing the great work! Thank you.'* (28 yo female). She attended the group in June 2022 and has since qualified as a teacher, which was one of her goals for attending the programme.



2024 meeting dates:

All meetings take place from 10am - 11.30am

- **Monday 29 January**

Featuring Kerry Davies speaking about the work she has done with the Royal College of Speech and Language Therapists (RCSLT) creating educational tools and resources on the communication challenges and difficulties in those with Long Covid.

- **Thursday 21 March**
- **Tuesday 21 May**
- **Wednesday 10 July**
- **Friday 20 September**
- **Tuesday 19 November**

To book your place or to find out more go to:

<https://qni.org.uk/news-and-events/events/long-covid-nurse-group-meeting/>

Thank you to all delegates who attended today's meeting.

FEEDBACK:

Thank you everyone. Very enjoyable session.

Thanks you for your time and presentations, most useful.

Brilliant sessions, thank you so much.

Good to be part of this session. Thanks Helen for the invite. Thanks Pip and Anne for your presentations. Useful to spend the time out of our usual activities for CPD and professional /personal reflection.

Thank you for another excellent meeting.

Fantastic presentation, thanks

Very interesting, will feedback to my OH colleagues

