



Reader Panel

Newsletter

This newsletter shares some of the work the Reader Panel have completed over the last six months supporting the Trust to deliver better health literature.

Thank you to all Reader Panel members.

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‘What’s Your Plan?’

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BENEFITS OF ADVANCE CARE PLANNING

- Your choice, voice & values.
- Make your wishes & values known.
- Keep control over your care.
- You have a plan, made together with your healthcare team.
- Peace of mind.
- Supports important conversations.

REMEMBER

Thinking about Advance Care Planning is beneficial for everyone. It ensures that your voice is heard and respected, even if you can no longer make decisions or communicate your wishes.

NEUROLOGY UNIT

Commencing Advance Care Planning conversations may feel challenging and emotional. The team are here to support you and it will help us to help you now and in the future.

FOR MORE INFORMATION:

- The Department of Health website explains Advance Care Planning in detail. You will find videos and information in a range of languages and formats.

www.health-ni.gov.uk/advance-care-planning-now-and-future

- The Neurology Unit Team are happy to answer your questions and provide information to you, your family and friends.

028 95040177 / 028 95040699

Advance Care Planning

WHAT'S YOUR PLAN?

**NEUROLOGY UNIT
MUSGRAVE PARK HOSPITAL**

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WHAT IS ADVANCE CARE PLANNING?

Advance Care Planning means that you have conversations about what is important to you about your future. It focuses on 4 main areas -

Personal Finance Clinical Legal

Advance Care Planning allows you to

- Ask questions about your condition, how it might change over time and decisions you may want to consider.
- Plan your future.
- Discuss and make choices about your wishes, feelings, values and beliefs.
- Discuss which medical treatments you would and would not want in the future.
- Discuss your wishes with your healthcare staff and the people who are important to you.
- Record your wishes in writing.
- Reflect on, change and update your written plan.

IT STARTS WITH A CONVERSATION..... Here are some ideas...

FINANCIAL

- Planning for Retirement
- Making a Will
- Probate
- Planning for Care

PERSONAL

- Online accounts
- Spirituality
- Care and support for dependants
- Funeral wishes
- What matters to me

CLINICAL

- Resuscitation for CPR
- Organ donation
- Best decisions in medical crises
- Best interests decisions
- Building trust & transparent relationships

LEGAL

- Advance directives for future treatment
- Mental Capacity Act (MCA) 2005
- Types of Power of Attorney

Advance Care Planning: For Now and For the Future, Department of Health

Advance Care Planning

Living for today planning for tomorrow

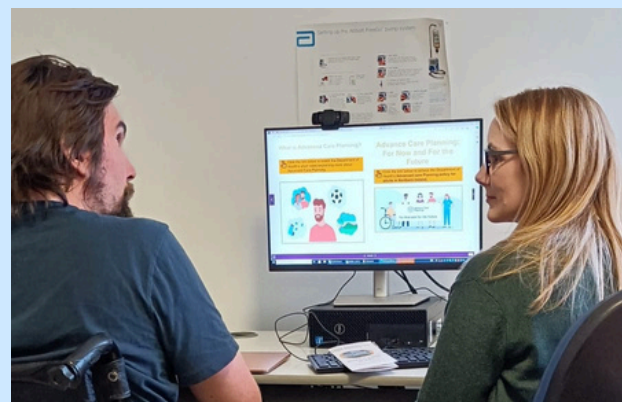
WHAT'S YOUR PLAN?

ADVANCE CARE PLANNING IS

- An essential conversation for everyone.
- Important for every adult at all stages of life.
- Thinking about what is important to you and planning your future.
- A series of conversations that makes your preferences for your wishes clear.
- Simple & straightforward.

ME

1. Think
2. Talk
3. Write
4. Share



“We were truly overwhelmed by the amount of thought and effort the panel put into reviewing our leaflet.”

'What's Your Plan?'

Advanced Care Planning

Julie Bray, Service Improvement and Governance Lead Occupational Therapist and Glenda King, Advanced Practitioner Dietician - Regional Neurology Unit, Musgrave Park Hospital

The Regional Neurology Unit in Musgrave Park Hospital required a review of their Advanced Care Planning leaflets. With such an emotive topic it was invaluable to hear back from the Reader Panel about how the information was received and made them feel.

The Reader Panel reviewed the layout, colours, style and spacing of text and graphic boxes. Wording was changed in several sections and contact details were added.

"When you are working on an information resource for someone else you know all the information/full story behind it and it is difficult to get the right amount and detail on a short leaflet to tell the full story – the reading panel ensured we managed that."

The leaflets are now finished and printed. They are available to everyone attending / visiting the Regional Neurology Unit.

Julie and Glenda said they would definitely use the service again and would recommend to others: "They were so quick to get back to us, the wide range of opinions and detail was invaluable... the input from such a diverse and wide ranging panel really helped develop resource that everyone to be able to avail off."

Discharge Information for Amputees

Review of information pack



“I would absolutely use this service again.. I see it as a necessary step when designing information to provide to patients”

Discharge information pack for amputees

Helen Brannigan, Clinical Specialist Physiotherapist in Amputee Rehabilitation, Musgrave Park Hospital

In March this year the Reader Panel reviewed the Discharge Information Pack for Amputees for the Physiotherapy Department in Musgrave Park Hospital.

Following Reader Panel input, the physiotherapists made changes to the wording and layout.

The Physiotherapy team had assumed their leaflet was suitable for service users but the Reader Panel advised making some changes. This was very useful and the input led to increased confidence that the leaflets were appropriate to give to service users.

When asked if Helen and her team would use the Reader Panel again she said “Absolutely, I see it as a necessary step when designing information to provide to patients.”

Terms of reference for the Disability Committee Review

 Belfast Health and Social Care Trust Working supporting improving together	
TERMS OF REFERENCE	
COMMITTEE	Disability Committee
BACKGROUND	The Disability Discrimination Act 1995 ("DDA") means that Belfast Trust must promote positive attitudes towards disabled persons, and encourage participation by disabled persons in public life. This applies to how we provide our services, how we employ our staff and how we spend money on other services. The group is made up of internal and external members to make sure we not only comply with the law but also embed and share best practice across the Trust.
PURPOSE	The purpose of the Disability Committee is to provide strategic leadership and direction to ensure that the Belfast Health and Social Care Trust fulfils its legal requirements with regard to employment and service provision. The Trust's Director of Performance, Planning and Informatics is responsible for the development and implementation of the Trust's Disability Action Plan and the Committee will ensure a partnership approach to this and will review progress of implementation and communication of the actions in the Disability Action Plan. The Trust's Corporate Planning and Equality Lead and the Chief Executive of Disability Action now co-chair the steering group.
DUTIES	1. Promote commitment at a corporate and strategic level for a collaborative, partnership approach to promoting best practice for disabled people, with the direct involvement of disabled people. 2. The group will provide leadership and direction and ensure commitment and accountability in the development, implementation and evaluation of the Trust's Disability Action Plan. 3. Provide the necessary support, resources and infrastructure to ensure an integrated and cohesive approach to the development, promotion, implementation, monitoring and evaluation of a range of initiatives as set out in the Disability Action Plan. Sub groups may be established to take forward specific initiatives to maximise impact. 4. Ensure the submission of an annual progress report for approval by the Trust Board and Executive Team and then to the Equality Commission for Northern Ireland as required by law 5. Manage an effective consultation, engagement and communication strategy to ensure that all issues associated with disability and what the Trust is doing are widely and effectively shared internally and externally. We will seek and take account the views of disabled people, including children and young people with disabilities and people with learning disabilities, in our Trust consultations and policy changes 6. To introduce employability initiatives set out in the Disability Action Plan and Employment Equality and Diversity Plan, in particular the implementation of the Trust Policy on the Employment of People

“It was very useful to have objective feedback to improve accessibility of the language used – particularly important for many of the members of the committee, who are not part of the Trust and some of whom have disabilities”.

Terms of reference for the Disability Committee

Orla Barron, Interim Co Director, Planning and Equality, Planning, Performance and Informatics

Orla Barron is the Interim Co-Director, Planning and Equality in the Planning, Performance and Informatics Directorate in the Trust and chairs the Disability Committee. This committee has a wide reaching membership from different organisations and members who have different needs in relation to communication.

The Terms of Reference (TOR) for the group were to be reviewed and the Reader Panel were asked to help.

The Reader Panel were able to provide suggestions to ensure the Terms of Reference were more accessible and less 'jargonistic' language was used throughout the document.

This helped support better accessibility for members.

Orla felt the process of including the Reader Panel had been really useful: "To have objective feedback to improve accessibility of the language used is particularly important for many of the members of the committee, some of whom are not part of the Trust and some have disabilities".

Orla would use the Panel again and recommend to others. "I suggested to all other members of the Involvement Group to submit their TOR to the Reader Panel to improve them".

Axial Spondyloarthritis /Ankylosing Spondylitis (AS) Creation of questionnaire

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Have your say... what matters to you?

Our Rheumatology Physiotherapy Team are hoping to improve our service for people with Axial Spondyloarthritis / Ankylosing Spondylitis (AS).

Every single person with AS will have a different experience.

We would like to know your views and experiences from time of diagnosis onwards.

Your feedback will tell us what is important to you. It will influence how we can make your experience better.

What you tell us is anonymous and taking part is voluntary.

We would really appreciate if you could take a few minutes to complete the attached questionnaire. Please scan the QR code above if you would prefer to fill it out online.

Would you be interested in future sessions where you share your experiences? If so, please leave your contact details below and will be in touch.

Your details will be stored separately to keep your questionnaire anonymous.

I agree to Belfast Trust Rheumatology Physiotherapy Service contacting me in relation to their ongoing service improvement work.

First Name	
Surname	
Address	
Telephone/Mobile	
Email address	

If you agree for us to hold your name on such a list, please be assured that this will be kept in strictest confidence in accordance with the Data Protection Regulations and will not be shared with anyone outside the Trust. It is completely voluntary and you can withdraw your permission at any time by contacting us.

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Have your say... what matters to you?

The Rheumatology Physiotherapy Team are reviewing their Axial Spondyloarthritis / Ankylosing Spondylitis (AS) service and would like to know about your views and experiences.

What you tell us is anonymous and taking part is voluntary.

1. How long ago were you diagnosed with AS?

2. Where were you diagnosed?

3. Thinking back to when you were diagnosed, do you agree with the following?

	Yes	No
I felt listened to	☐	☐
I could ask questions	☐	☐
I could understand everything	☐	☐
I was involved in decisions	☐	☐
I could discuss my concerns	☐	☐

4. How satisfied were you with your experience of being diagnosed with AS?

0	1	2	3	4	5	6	7	8	9	10
Not at all Satisfied	☐	☐	☐	☐	☐	☐	☐	☐	☐	Extremely Satisfied

What would have made this better?

5. Thinking about AS, which topics are important to you?

Pain	☐	Exercises to help AS	☐
Work	☐	Low mood	☐
Medication	☐	Impact on family and friendships	☐
Fatigue	☐	Concerns for the future	☐
Stress	☐	Lifestyle e.g. smoking, alcohol, sleep etc.	☐

6. When would information about AS be most useful?

At the time of diagnosis	☐	Within 1-2 months	☐	At a later appointment	☐
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“Having multiple external opinions was really helpful to highlight areas that may not have been clear to our patients”.

Questionnaire - Axial Spondyloarthritis (Ankylosing Spondylitis)

Niamh Kennedy, Advance Practice Physiotherapist, Rheumatology & Aquatic Therapy, Royal Victoria Hospital

Niamh Kennedy works in the Rheumatology Physiotherapy Team. The team were working to improve their service for people with Axial Spondyloarthritis (Ankylosing Spondylitis) or 'AS'.

The team created a questionnaire to better understand the experience of people who use their service. As a result of the Reader Panel input the team has re-worded a number of questions and restructured parts of the questionnaire information.

Niamh and the team felt the process of engaging the Reader Panel in their work had been useful.

“There were a number of suggestions made that we completely agreed with and came from a perspective that we hadn't seen ourselves. Some of the suggestions made perfect sense and were very clear. It was also very nice to receive some positive comments which really encouraged and motivated us. Having multiple external opinions was really helpful to highlight areas that may not have been clear to our patients”.

The service now have a more accessible questionnaire. The questionnaire has been sent to 110 people and received 27 responses so far. Excellent information is now in place to guide how they make service improvements going forward.

Niamh says they would defiantly use the Reader Panel again and recommend to others.

Testimonials

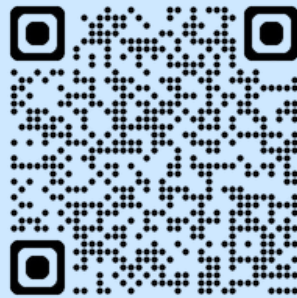
Here are some comments from staff about their experience involving the Reader Panel.

“We were truly overwhelmed by the amount of thought and effort the panel put into reviewing our leaflet.”

“I would absolutely use this service again. I see it as a necessary step when designing information to provide to patients.”

“It was very useful to have objective feedback to improve accessibility of the language used – particularly important for many of the members of the committee, who are not part of the Trust and some of whom have disabilities”.

“Having multiple external opinions was really helpful to highlight areas that may not have been clear to our patients”.



Trust Teams - would you like to use the Reader Panel to improve your service?

Service users or carers - would you like to join the Reader Panel to shape Trust information?

For more information about the Reader Panel contact us. email:
PPI@belfasttrust.hscni.net
or phone: 028 95 044501

Personal and Public
Involvement (PPI)



Involving you,
improving care