

Information for patients and carers

Advanced Care Planning for people with
Parkinson's Disease/Parkinsonism's -
Multiple System Atrophy (MSA), Progressive
Supranuclear Palsy (PSP) and Corticobasal
Degeneration (CBD)

Parkinson's Team – Central Lancashire

A decorative graphic at the bottom of the page consisting of three overlapping, wavy bands of blue color, transitioning from a lighter blue at the top to a darker blue at the bottom.

This leaflet provides information about advanced care planning for those who have had a diagnosis of Parkinson's or Parkinsonism's, and for their family or carers who support them.

Who are the members of The Parkinson's Team?

- Consultant Neurologist
- Parkinson's Clinical Nurse Specialists
- Parkinson's Independence co-ordinator (Age UK)
- Admin Support

What is an Advanced Care Plan?

Even if you are at the start of your Parkinson's journey it is important to consider the care you may want or need in the future and would like to receive as your Parkinson's progresses. Also, your future wishes, which you should consider discussing with your family, friends and any healthcare professionals involved in your care. These can all be documented in the form of an Advanced Care Plan

It is your choice whether you wish to make an advanced care plan or not. Never feel pressurised into completing one or adding something to the plan that you don't wish to include, it is important to remember that this is your advanced care plan, and you can make changes to it should you wish to.

How do I make an Advanced Care Plan?

You can write down your wishes with your healthcare professional who may have a template form to help with the process and cover all aspects to be considered, this can make it easier to follow your wishes in the future.

You don't need to write your wishes down in a formal manner if you don't want to, you could choose to discuss your wishes with family, friends and healthcare professionals without writing them down.

What is involved in Advanced Care Planning?

Advanced care planning should include anything you feel is important to you:

- How would you like to be cared for?
- Where would you like to be looked after in the future and in your final days?
- Are there any spiritual or religious beliefs that should be considered?
- Who should your doctors or nurses talk to about your wishes if you become unable to make decisions?
- Do you have a lasting Power of Attorney?
- Is there anything else that is important to you that you would like to be included?

Will my Advanced Care Plan be followed?

Having an advanced care plan makes it more likely that your wishes will be followed. It is important to know that it is not legally binding and there could be circumstances when the doctors or nurses attending you don't follow the wishes you've recorded.

Making choices about the care you receive

You may feel that there are certain treatments or interventions that you would prefer not to receive this can be discussed and documented in your advanced care planning.

Who will see my Advanced Care Plan?

Your advanced care plan will be shared with your consent to your GP and other healthcare providers involved in your care.

Where are we based?

Regional Neuroscience Centre
Lancashire Teaching Hospitals
Royal Preston Hospitals
Sharoe Green Lane
Fulwood
Preston
PR2 9HT
01772 523575

Sources of further information

www.lancsteachinghospitals.nhs.uk

www.nhs.uk

www.accessable.co.uk

www.patient.co.uk

www.parkinsons.org.uk

www.msatrust.org.uk

www.pspassociation.org.uk

www.mariecurie.org.uk

www.ageuk.org.uk

References

Marie Curie – Planning ahead (2021)

<https://www.mariecurie.org.uk/globalassets/media/documents/how-we-can-help/living-with-a-terminal-illness/planning-ahead.pdf>

Parkinson's UK – Parkinson's: Preparing for end of life (2016)

https://www.parkinsons.org.uk/sites/default/files/2023-07/INFOB0027%20Preparing%20for%20end%20of%20life_2023_FINAL.pdf

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www.lancsteachinghospitals.nhs.uk/patient-information-leaflets

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If you want to stop smoking, you can also contact Smokefree Lancashire on Freephone **08081962638**.

Please ask a member of staff if you would like help in understanding this information.

This information can be made available in large print, audio, Braille and in other languages.

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Division: Specialist Medicine

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