



Navigating health **information** and **services**

**For patients, families
and caregivers**

where
science
meets **humanity**™

Be informed. **Be engaged.**

When it comes to your health, playing an active role in decision making can bring many benefits. Working in partnership with healthcare professionals can help you be informed about your condition and involved in decisions about your care. Evidence shows that it can also lead to improved clinical outcomes.¹ However, there is a huge amount of information available from many different places and it can be difficult to know which resources are credible and trustworthy.

This brochure will outline some of the important considerations when discussing your health with healthcare professionals.

The following information provides guidance on:

- 1 Working in partnership with healthcare professionals**
- 2 Finding reliable healthcare information**
- 3 Understanding how to manage your health**



1

Working in partnership with healthcare professionals

Being able to have clear, open and honest conversations with healthcare professionals will help them to understand your priorities and make the best use of the time available at the appointment.

The role of the healthcare professional

Healthcare professionals will provide information about the different options available to manage your condition, including the anticipated benefits and any risks that should be taken into consideration. If you don't understand something which your healthcare professional has said, ask them to rephrase it in a simplified way.

The role of patients and caregivers

Think about how to convey your personal preferences, personal circumstances, goals, values and beliefs.² You can help your healthcare professional understand the impact that the condition has on your quality of life by explaining how it affects you on a day-to-day basis. With this in mind, you will be able to have more informed, constructive and open conversations with healthcare professionals.

Before attending an appointment or having a discussion with a healthcare professional, here are some actions to consider:³

- Prepare a list of questions you want to ask before the appointment
- During the appointment, take notes or ask the healthcare professional if they're happy for you to record the conversation using a phone, so you can listen back to what was discussed
- Focus on your quality of life and describe the daily obstacles you face and how they affect your wellbeing
- Be honest and use your own language to describe symptoms and how you are feeling
- Think about the desired outcome of the appointment

2

Finding reliable information about healthcare options

Finding reliable information

It is important when seeking medical information, whether online, in print or face-to-face, to remain cautious and refer to reputable sources for advice that is relevant to your specific disease and personal characteristics. Healthcare professionals should be the primary source of information but patient advocacy groups are typically reliable sources of information, education and support. In addition, online information published by relevant healthcare systems, government or hospital is also generally trustworthy and can help guide decision making.



Access points for reliable information:

- Healthcare professionals
- Patient advocacy groups
- Government organisations
- Non-profit health organisations

3

Evaluating options to effectively manage your health

Every patient is different, and when thinking about how to best manage your health and preferred care options, it's important to consider personal goals, health, lifestyle and quality of life.

Your healthcare professional will identify the available care options and discuss what is most important to you when it comes to health management. It could be:

- slowing down the disease
- controlling or improving symptoms
- long-term, rather than short-term impact
- convenience of the care options (how, where and how often)
- potential adverse events or side effects

The photographs used in this brochure are real patients and the required consent to use their pictures/stories has been obtained from the patients and families. Photographs are for illustrative purposes only.



In short:

Considerations for your care

- What are the benefits?
- What are the risks?
- What are the long-term vs. short-term considerations?

It is important to discuss with a healthcare professional if you have any questions about the management of your health.

1. De Santis, M., Herva, C., Weinman, A., Bosi, G. and Bottarelli, V., 2019. Patient empowerment of people living with rare diseases. Its contribution to sustainable and resilient healthcare systems. *Annali dell'Istituto superiore di sanita*, 55(3), pp.283-291
2. NHS. Shared decision making. [Internet; cited 2020 March]. Available from: <https://www.england.nhs.uk/shared-decision-making/>
3. NHS. What to ask your doctor. [Internet; cited 2020 March]. Available from: <https://www.nhs.uk/using-the-nhs/nhs-services/gps/what-to-ask-your-doctor/>

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