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Today's talk

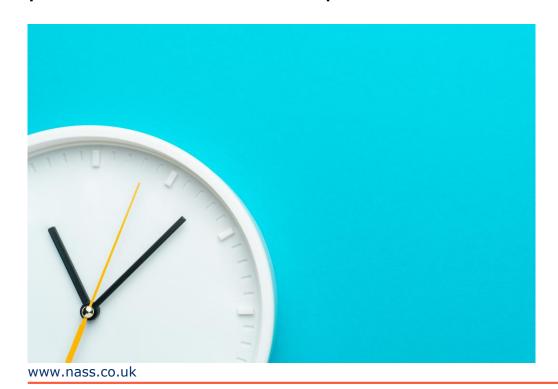
- Short presentation about getting the most out of medical appointments
- Slides and useful links shared after the live
- Feel free to get involved in the comments ask questions and share your experiences



Today's talk

With limited time in medical appointments, we wanted to share advice on getting the most out of them

Lots of this information comes from people living with axial SpA and healthcare professionals – Your SpAce



If you've recently been diagnosed, remember that it takes time to understand your condition and get used to medical appointments – over time it will get easier



Preparing for medical appointments

It's normal to feel a mixture of emotions before, during, and after an appointment

Preparing well beforehand can help with any feelings of anxiety or overwhelm, as well as give you the best chance of getting the most out of the appointment

Check the hospital website or your appointment letter for important information

Remember, you may not see the person named in the appointment letter on the day



The practicalities

Research the practicalities in advance:

- How you'll get to the appointment
- Aim to arrive early, allowing time for parking and getting from the hospital entrance to the department
- Allow plenty of time for the appointment clinics can run late, you may be sent for extra tests, etc



Online or telephone appointment



For an online or telephone appointment:

- Prepare as you would for an inperson appointment
- Ensure you have somewhere quiet and private
- Make sure you're free from distractions



Reflecting beforehand

A couple of weeks before, set aside time to prepare and make notes. You may like to consider:

- What was discussed at your last appointment
- How things have changed since your last appointment
- Anything you've been struggling with?
- What's been going well?
- Medication how well it's working and any side effects?





Reflecting beforehand

- What you've been doing between appointments to manage your symptoms
- How your condition is affecting you at night, the quality of your sleep
- How you're managing work or hobbies
- How your condition is affecting your social life
- Other symptoms you're experiencing, e.g. skin, gut, or eye symptoms
- How you're coping emotionally
- Anything that's coming up in the future, e.g. big life changes or planning to start a family



To help reflect back



It can be difficult to remember what's happened since your last appointment. It can be helpful to:

- Track your symptoms between appointments
- Ask friends and family if they've noticed anything



Make a list

Once you've reflected back, use our preparation worksheet to:

- Make a list of all the things you'd like to discuss
- Mark down the top 2-3 priorities for you

If your hospital sends you questionnaires or forms to complete, do this before your appointment



Attending the appointment



You're welcome to take a friend or family member along with you – but consider what you'd like to discuss and who you're comfortable having present

Take your list with you and explain to your healthcare professional at the beginning of the appointment that you have key things you'd like to discuss



During the appointment

You may like to take notes of anything key or important you discuss – but your healthcare professional will usually send a letter after the appointment

If you're feeling overwhelmed, ask for written information or further resources

If something has been missed or you don't understand, ask the healthcare professional to go over it again

- you can keep a note and revisit it at a future appointment if helpful



Immediately after an appointment

You may like to use our appointment reflection worksheet to make notes on:

- How you felt the appointment went
- Anything you didn't cover
- Any follow up questions you may have



Allow yourself time to do something relaxing or fun



If the appointment didn't go as well as you'd hoped

Sometimes you leave an appointment feeling you didn't get what you wanted or needed from it. There are some useful steps you can take:

- 1. Reflect on exactly what didn't go well or was missing
- 2. If it's something that can't wait until your next appointment, contact the clinic helpline/email address or your healthcare professional's secretary to share
 - they may be able to resolve it
 - you may be offered a telephone conversation or appointment
 - you may be referred to another healthcare professional best suited to help
- 3. If you've had concerns about being listened to or feel there's an issue with the patient-clinician relationship, contact the hospital Patient Advice and Liaison Service (PALS)
- 4. You can also contact the NASS Helpline or visit the website



Support between appointments



Ask the hospital if they have an app or system you can use for recording your symptoms between appointments

Ask if they have an advice line you can call between appointments – it's important to know:

- Who you can contact
- How you can reach them
- What they're able to assist with



Information and resources – useful links

Your SpAce – getting the most out of appointments

Resource sheets to:

- Prepare for an appointment
- Make notes during an appointment
- Reflect after an appointment

Download a copy to <u>print and fill in by hand</u> or download a copy to <u>fill in electronically</u>

Understand more about <u>Patient Initiated Follow-up appointments (PIFU)</u>



Key takeaways

- If helpful, track symptoms between appointments
- Take time to prepare for an appointment
- If comfortable, take a loved one with you to your appointment
- Take time not only to reflect after an appointment, but to do something fun or relaxing
- Seek support or advice if needed
- Remember to reflect on and celebrate your wins, what's going well, and the practical things you're doing to manage between appointments



Thanks for listening

Any questions?

