

AS MANAGEMENT TRACKER

TAKING

CONTROL

OF

**ANKYLOSING
SPONDYLITIS**

**BACK
YOUR
SELF**

**TAKING
CONTROL
OF AS**



IT'S TIME TO BACK YOURSELF

This guide aims to help you have clear and honest conversations with your healthcare professionals about how ankylosing spondylitis (AS) is impacting your life. Even if it's been a while since your last appointment, sharing your goals with confidence is the first step to taking control of AS, and getting back to the life you love.

Your doctor is your best ally in taking control of ankylosing spondylitis. However, you can also use this guide to have good conversations with any therapist or allied health professional who help you manage your AS.

1. SHARE YOUR GOALS

A good way to back yourself is to start by thinking about the life you want to live and setting clear, realistic goals. After this, you can work with your doctor develop a shared management plan to help you work towards achieving them.



Here's some examples for inspiration:

**I WANT TO GET BACK
TO THE GYM/YOGA/
SWIMMING** ~

**I WANT TO GET
BACK TO SLEEPING
THROUGH THE NIGHT**)

**I WANT TO GET BACK
TO PLAYING WITH THE
KIDS LIKE I USED TO**

**I WANT TO GET
BACK RUNNING
REGULARLY** =

**I WANT TO GET
BACK TO FEELING
LIKE MYSELF/
HAPPIER IN MYSELF** //

**I WANT TO GET BACK TO
DOING A REGULAR "DAY"
AT WORK WITHOUT
FEELING VERY TIRED**

In the coming months, I want to get back to...

2. EVALUATE YOUR CURRENT ACTIVITY

Thinking about any physical challenges you've faced in the last week, share whether the following activities feel within reach.

Difficulty on a ten-point scale (1 is easy and 10 is impossible)¹

Please indicate your level of ability with each of the following activities during the past week.

Putting on your socks or tights without help or aids (e.g., sock aid).

Bending from the waist to pick up a pen from the floor without aid.

Reaching up to a high shelf without help or aids (e.g., helping hand).

Getting up from an armless chair without your hands or any other help.

Getting up off the floor (without help) from lying on your back.

Standing unsupported for 10 minutes without discomfort.

Climbing 12-15 steps without using a handrail or walking aid.

Looking over your shoulder without turning your body.

Doing physically demanding activities (e.g., physiotherapy exercises, gardening or sports).

Doing a full day's activities at home or at work.

Now think about how AS is impacting you.

Please place a mark on each line below to indicate your answer to each question relating to the past weekⁱⁱ.

1. How would you describe the overall level of fatigue/tiredness you have experienced?

NONE VERY SEVERE

2. How would you describe the overall level of AS neck, back or hip pain you have had?

NONE VERY SEVERE

3. How would you describe the overall level of pain/swelling in joints other than neck, back, hips you have had?

NONE VERY SEVERE

4. How would you describe the overall level of discomfort you have had from any areas tender to touch or pressure?

NONE VERY SEVERE

5. How would you describe the overall level of morning stiffness you have had from the time you wake up?

NONE VERY SEVERE

6. How long does your morning stiffness last from the time you wake up?

0 HRS ½ 1 1½ 2 OR MORE HOURS

3. EVALUATE YOUR CURRENT MANAGEMENT PLAN

It's important you tell your doctor if your current management plan is helping you, as well as telling them about any concerns you might have about your treatment, or quality of life. Also, be sure to share if you've experienced side-effects or if you've had a hard time adhering to your treatment regimen.

Use this table to think about your current management plan and how satisfied you are. Remember to think not just about medication (both prescription and over-the-counter medicines) but other therapies you may be using to manage AS such as physiotherapy, counselling, acupuncture, exercise etc. It's also important to tell your doctor if you are using other substances too e.g. alcohol.

Therapy type	Rating – rate whether this therapy is helping you 1= Not helpful 10= Extremely helpful	Notes - Any positives / challenges with this therapy?

4. TRACK YOUR SYMPTOMS

How you feel may vary day-to-day, so you should be ready to share how AS is impacting your life right now, and over time. Use the table below to track your symptoms for a few weeks ahead of seeing your doctor. In addition to symptoms like pain, stiffness and fatigue, don't forget to tell your doctor how AS may be impacting other areas of your life e.g. disrupted sleep, impact on daily activities, or changes in mood.

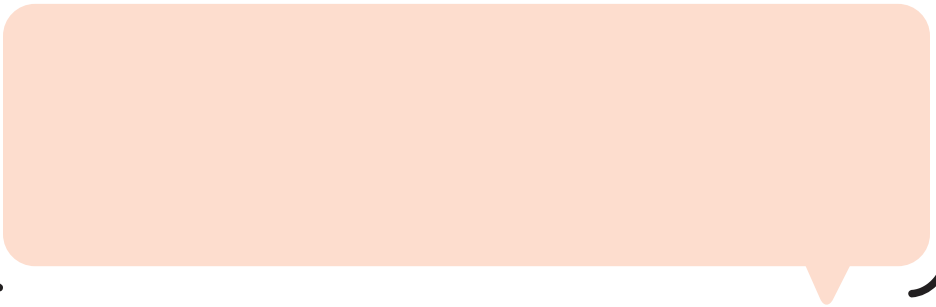
	Symptoms – what kind, severity, frequency	Impact on your daily life
Week 1		
Week 2		
Week 3		
Week 4		

5. BACK YOURSELF BY BEING PREPARED

With limited appointment time, it's important you feel ready to discuss your AS and how it's impacting your life in a clear and honest way. Here's three ways to back yourself in advance of your next conversation with your doctor.

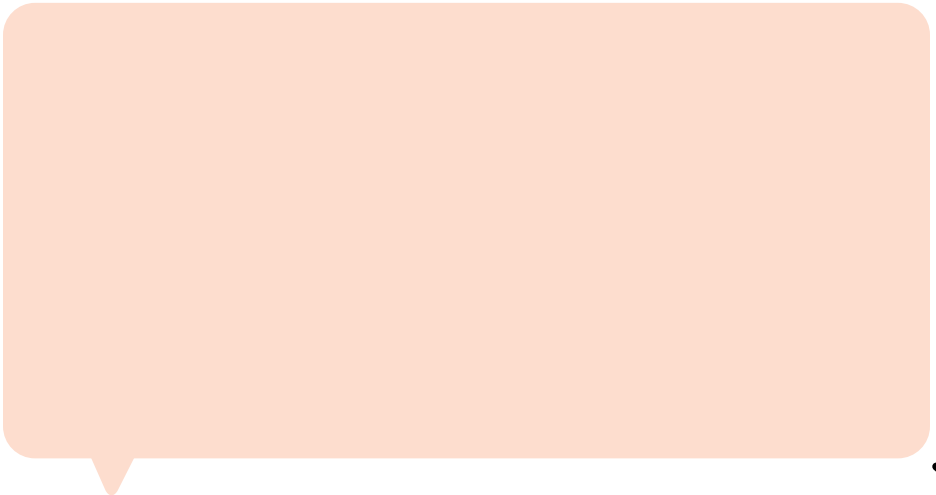
1. Think about the key thing you want your doctor to know.

It can be a challenge to remember everything all at once. Try to think about the key thing you'd like to share so your doctor knows what's most important to you.



2. Write down things you want to ask.

Writing down your questions and checking them off as you go will help ensure you cover what's important.



3. Bring everything you need.

If you've had x-rays or scans or blood tests etc, it's a good idea to take the copies and results with you to the appointment. If you have them with you, it means your doctor can look at them there and then and will mean you can make the most of your appointment.

Also, remember a specialist referral is only valid for 12 months so it is a good idea to check when you make an appointment if you need a new referral from your GP.

Here's a check list to help you remember everything:



SPECIALIST REFERRAL



BLOOD TEST RESULTS



**COPY OF ANY
SCANS OR X-RAYS**



**THIS CONVERSATION
GUIDE**

Need more support?

Backing yourself isn't always easy. But you should know that help is available. From expert guidance and real stories from people living with AS to helpful tools and more, find additional support at www.back-yourself.com.au





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**BACH
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¹Calin A et al. J Rheumatol. 1994 Dec;21(12):2281-5.

²Garret S et al. J Rheumatol. 1994 Dec;21(12):2286-91.