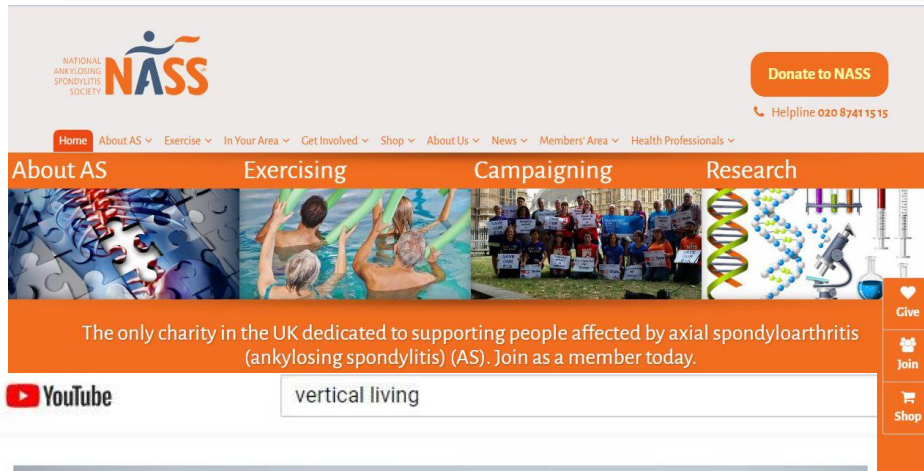
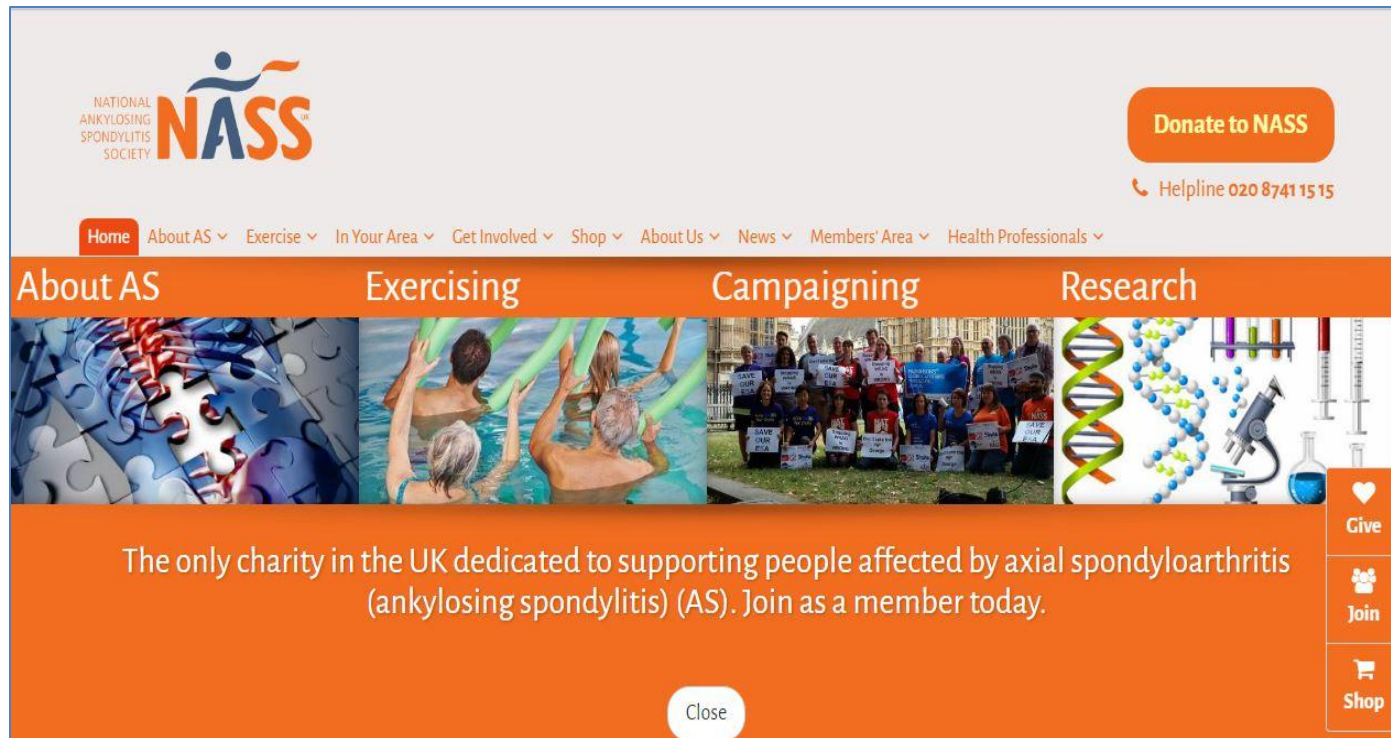


Websites, Apps and YouTube videos for Ax SpA and AS patients



Arthritis?! Isn't That For Old People! Well, no - My Experience with Ankylosing Spondylitis

www.nass.co.uk

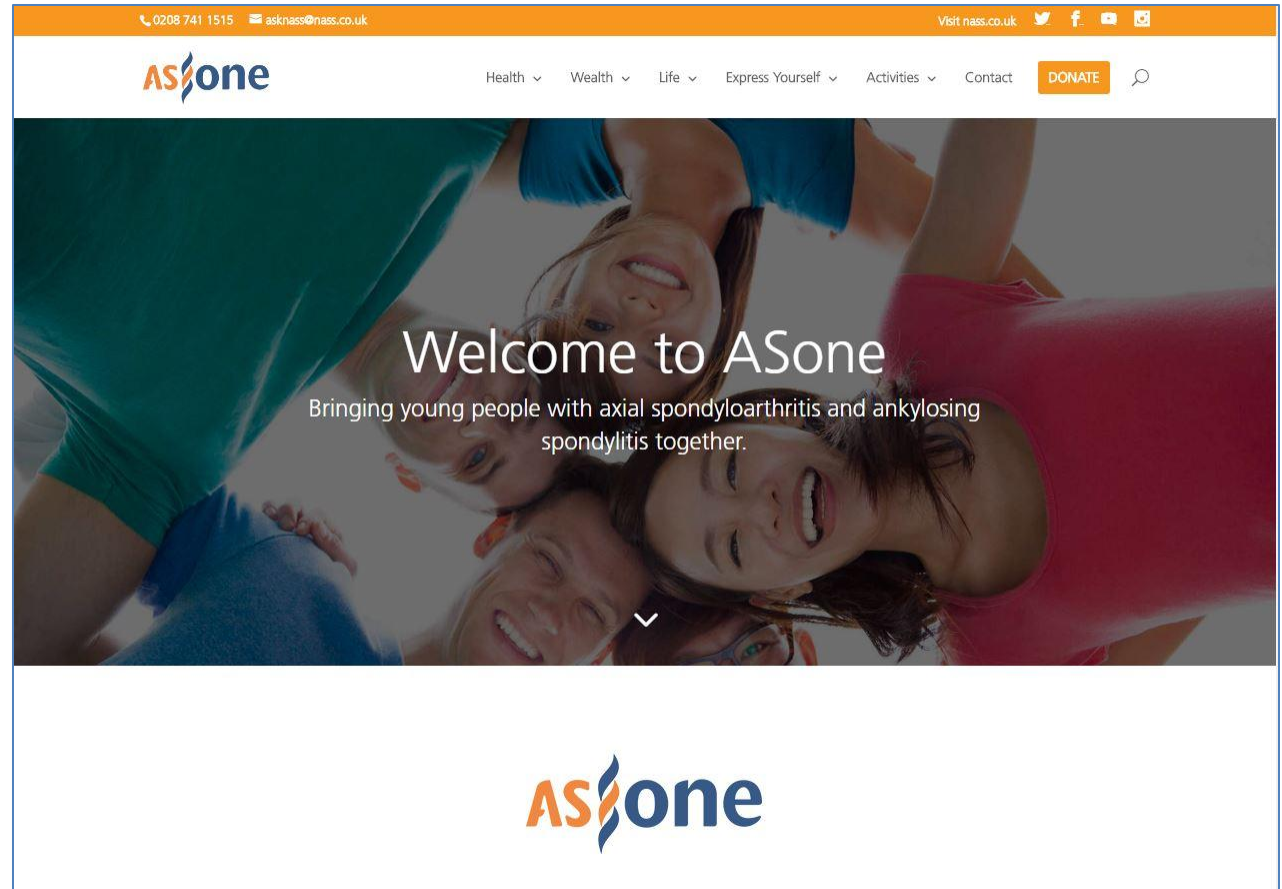


NASS website, my “go to” website for AxSpA / AS patients for reliable, up to date information. Brilliant to sign post newly diagnosed patients to or patients looking for a NASS group near them. Remember patients can download all the NASS fact sheets including how to manage fatigue, advice on flares, biologic therapy, information of uveitis and driving with AS and so much more!

www.asone.nass.co.uk

AS One is NASS's website geared to younger patients – from 18-30, but not exclusively.

It's format is quite different and has articles by guest bloggers and vloggers, designed to appeal it's younger audience.



Excellent website of bite size information via articles and videos.

The videos are 6 minute conversations conducted by Dan Reynolds from the band Imagine Dragons, who himself has AS, talking to other people with AS including his brother, a student a grandmother and a chef amongst others. Great to recommend to patients who perhaps are feeling isolated and have not met anyone else with AS before.

The articles are categorised into symptoms, staying healthy, tech and life style.

www.thisaslife.com

The screenshot shows the homepage of the website www.thisaslife.com. The layout is divided into several sections:

- Header:** A red bar at the top contains a "MENU" icon, the word "ENGLISH" with a dropdown arrow, and a "CONTRIBUTING EDITORS" section.
- Main Content Area:**
 - Left Column:** Features the "This AS Life" logo with the tagline "LEARN. SHARE. INSPIRE. DISCUSS." and the text "Advice from people in the know, Inspired by you". Below this is a "LIFESTYLE" section titled "AS-pirations" with the subtitle "The Importance of setting goals in AS and how best to achieve them", accompanied by a photo of a person's feet on stairs.
 - Center Column:** Displays the text "AS and #ThisASLife" with social media icons for Twitter, Instagram, and Facebook. Below this is a red box titled "AS AND THIS AS LIFE" with the text "Find out how This AS Life works. From patient, to expert, to patient. See how you can get in the loop." and a "READ MORE >" link.
 - Right Column:** Features a "LIFESTYLE" section titled "Going the distance" with the subtitle "Raj Mahapatra on where he found the strength to overcome AS and keep setting himself new challenges", accompanied by a photo of a person running.
- Contributing Editors:** A section on the right side of the page featuring four portraits of contributors: Gillian, Bjillian, Philip, and Fiona.
- Staying Healthy:** A blue box at the bottom right titled "STAYING HEALTHY" with the text "The Genslers on Ankylosing Spondylitis and Exercise" and "Physical Health and AS", accompanied by a photo of a couple sitting at a table.

www.spondylitis.ca

Worth looking at other countries AS Association websites, so for instance the Canadian Spondylitis association has produced a video of all the exercises from the NASS guidebook, which could be helpful to recommend to some patients.

Also there is a link to University Health Network Hospitals (UHN) who have created an eLearning course for AS patients or their family and care givers, who want to learn more about their condition. It is presented as a interactive power point presentation, with voice over and goes into quite a lot of informative detail. Only one word of warning, when talking about medication, it gives the North American drug names.

The screenshot shows the homepage of the Canadian Spondylitis Association website. The header is blue with the organization's logo and navigation links: Spondyloarthritis, Support & community, Get involved, The latest, and Who we are. Below the header, there's a breadcrumb trail: Home / [The latest](#). The main content area is titled 'Videos' with social media icons for Facebook and Twitter. A sub-header reads: 'Watch topic videos, patient forums, and seminars from the Canadian Spondylitis Association.' The featured video is titled 'Exercises for People with Ankylosing Spondylitis' and shows a person performing a stretch on a mat. The URL 'www.spondylitis.ca' is visible at the bottom of the video player. On the right sidebar, there's a section titled 'Support & Community' with a photo of a group of people. Below it, a link for 'Support & community' is provided, along with a brief description: 'Visit the pages within this section for more information and to find out how some of the w...'. At the bottom of the sidebar, there's a 'Your Story' section with a partial image of a person's face and a 'MORE' link.

www.ankylosing-spondylitis.ie

The Irish AS Association's website is quite wordy but does have a good section on posture; in standing, sitting, driving, in the kitchen, vacuuming, ironing and in office.

There is also an article on points to consider when choosing a mattress.

There is also an article on points to consider when choosing a mattress.



ASAI
Ankylosing Spondylitis
Association of Ireland

[HOME](#)
[ABOUT AS](#)
[AS SUPPORT ON THE GO:
SUAS SMARTPHONE APP](#)
[NEWS & EVENTS](#)
[GET INVOLVED](#)
[INFORMATION
BOOKLETS](#)
[RESOURCES](#)
[ABOUT ASAI](#)

AS SUPPORT ON THE GO

INTRODUCING THE
SUAS IPHONE APP







**NOW AVAILABLE
IN
ANDROID**

 Available on the
App Store

 Get it on
Google play



Get Involved

Get involved in your community with local events and activities to help keep you active and fit.

[Get involved ▶](#)



News & Events

Keep up to date with the latest AS news and events from around the country.

[See all events ▶](#)




Exercise classes

A comprehensive guide to your local exercise classes, including details, locations and timetables.

[See classes in your area ▶](#)

www.talkingas.com

Patients should be encouraged to sign up to *Talking AS* especially if your hospital is also signed up to it, as it is a way of monitoring your patient's Bath questionnaire scores in between clinic appointments. Patients can choose if they want to share their information with you or not. It will produce graphs over time so patients can monitor from home their symptom control and the effects of any medication changes or keep a record of any flares.



[Home >](#)
[Fill in assessment >](#)
[BASDAI >](#)

[Log in](#)
[Register](#)

[Fill in assessment](#)
[I have AS](#)

The Assessment

Introduction

There are a series of questions which will help you and your healthcare professional assess your ankylosing spondylitis and make sure that your condition is as well managed as possible. It's important to fill in the questionnaire as often as your healthcare professional recommends and to save your entries as you go. That way, they can look back at your previous result to see if anything has changed.

If you want to save your results you must be logged in.

The first seven questions ask about the main symptoms of AS – fatigue, back pain and morning stiffness. Use the numbers under each question to indicate how you feel best describes your condition. **Each question relates to how you have felt in the LAST WEEK.** There is no wrong answer.

Question 1

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

None

0 1 2 3 4 5 6 7 8 9 10

Very Severe

0%

Question 2

How would you describe the overall level of AS **neck, back or hip** pain you have had?¹

None

0 1 2 3 4 5 6 7 8 9 10

Very Severe

Question 3

How would you describe the overall level of pain/swelling in joints **other than** the neck, back or hips you have had?¹

None

0 1 2 3 4 5 6 7 8 9 10

Very Severe

My SpA App

My SpA app has been created by the Rheumatology Team at Whipps Cross University Hospital.

I particularly like the exercise library with over 40 exercise videos to choose from.

It also has a monitoring section where patients can monitor amongst other things their blood test results, BASDAI, BASFI, ASQoL, Global VAS, FACIT-F for patients to monitor their fatigue levels and also some PROMs for patients with PsA.



MySpA

Earthware Ltd Health & Fitness

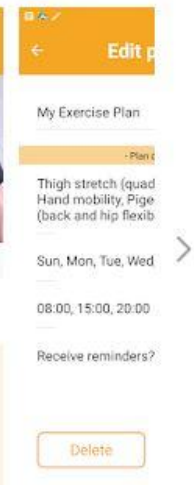
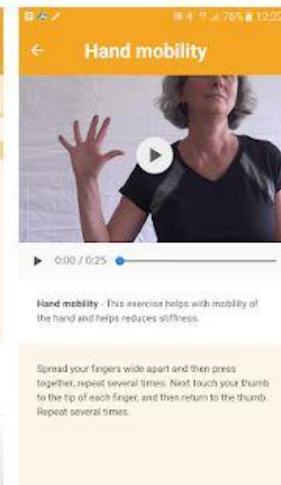
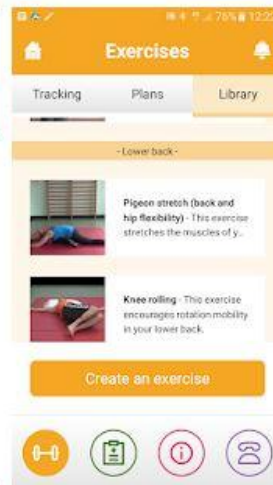
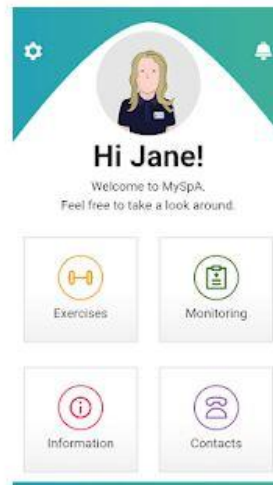
★★★★★ 5

PEGI 3

! You don't have any devices.

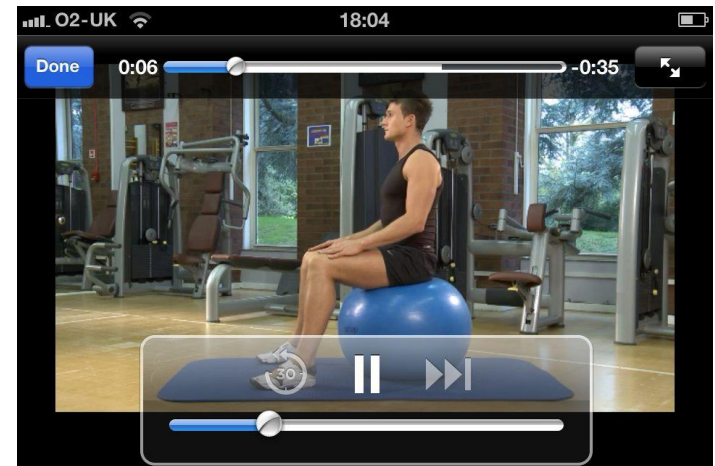
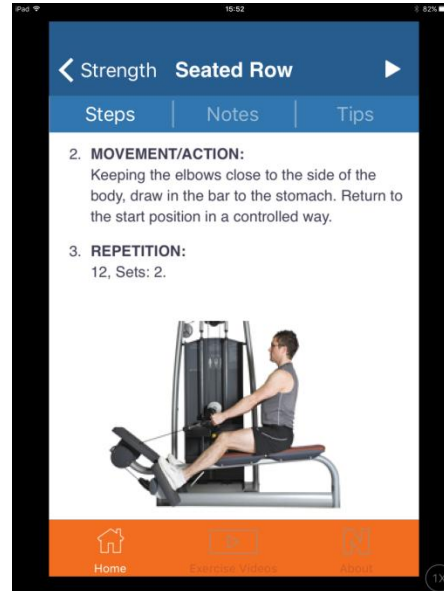
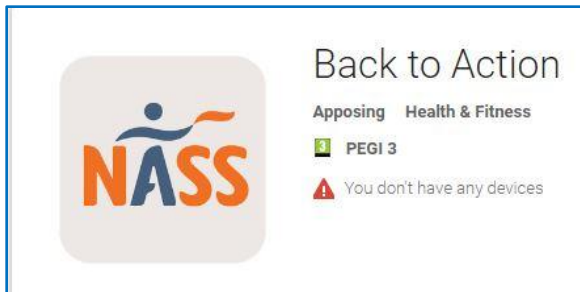
+ Add to wishlist

Install



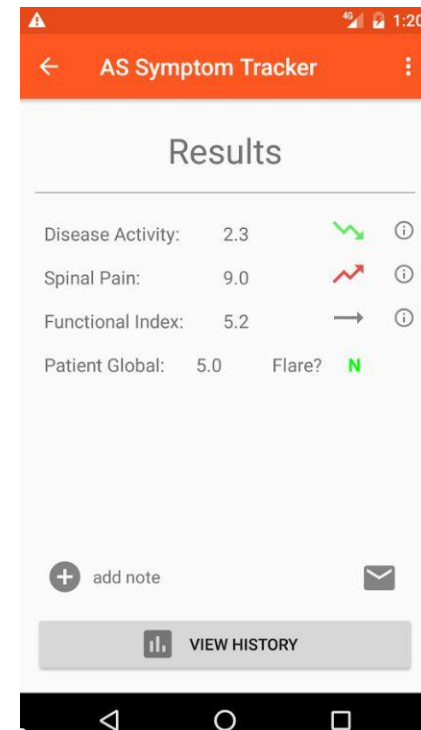
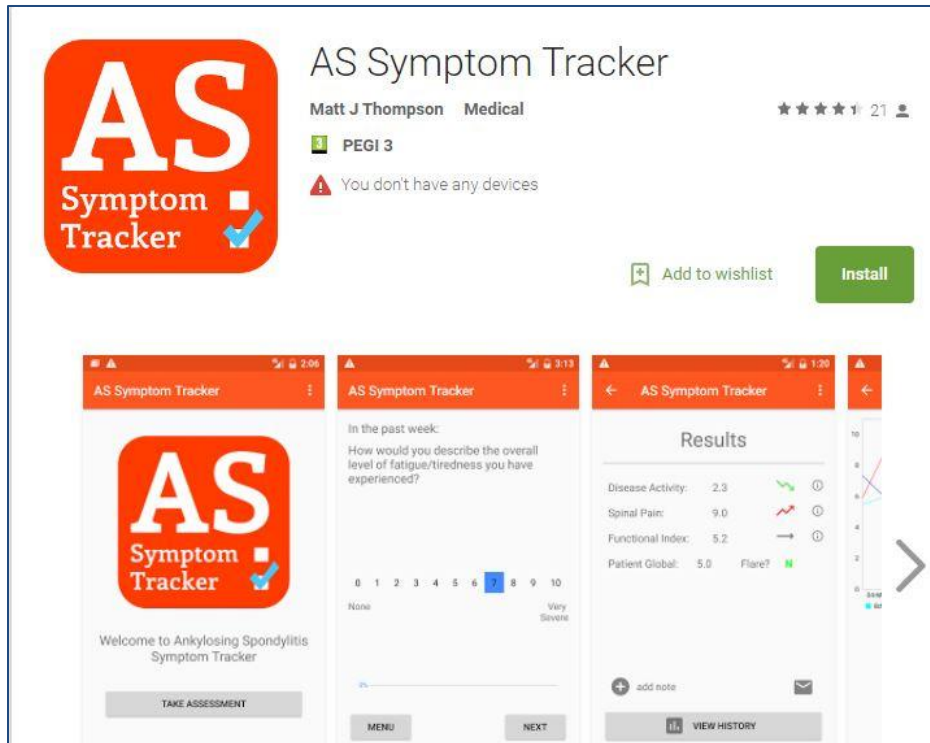
This App has been created by the Rheumatology Service at Whipps Cross University Hospital to provide instant access to medical information, exercises and assessments to help you manage your spondyloarthritis (SpA).

NASS Back to Action App



The *Back to Action* app is a free exercise app produced by NASS. It is specifically designed for people with AS who may want to exercise in the gym, but not exclusively as most of the exercises can be done at home as well. If patients are using it in the gym, then it shows the correct postures and recommended gym equipment to use. All exercises are demonstrated in photos with a clear voice over and most also have an accompanying video.

AS Symptom Tracker App

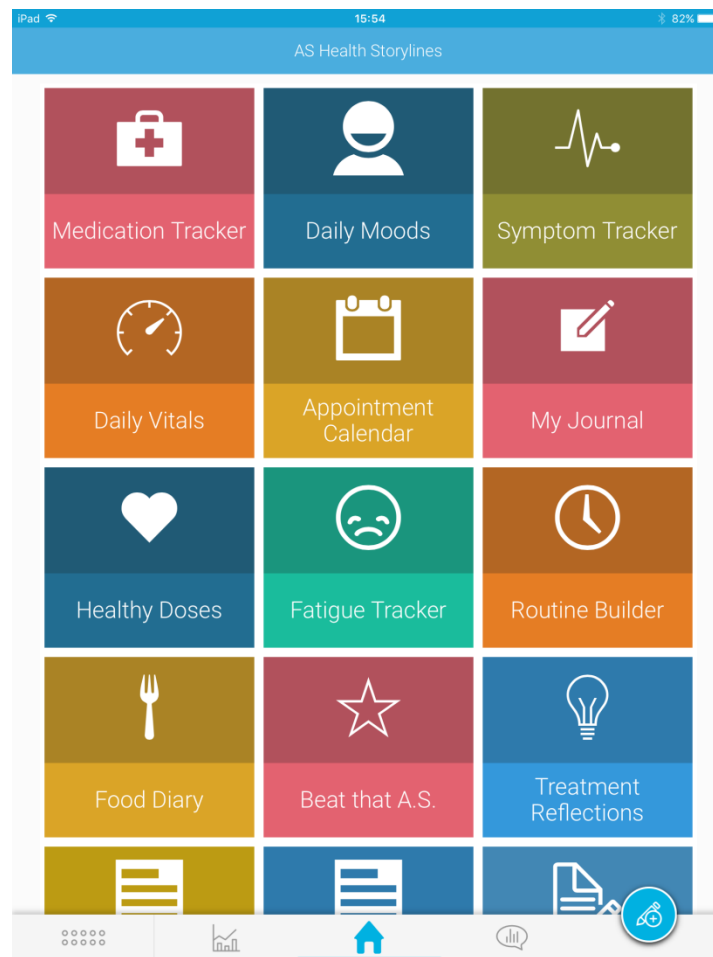


The *AS Symptom Tracker* app is a free app and was designed by an AS patient and Rheumatologist. It is not dissimilar to Talking AS, as it allows the patient to assess and keep track of their symptom severity using the Bath AS questionnaires. It also asks if the patient thinks he or she is in a flare. It says if their symptoms have improved or deteriorated and will produce a graph and can be backed up to a secure cloud. If the patient wishes they can email the results to their Rheumatology Team.

AS Health Storylines App



The *AS Health Storylines* app has been developed in partnership with people with AS and the Canadian Spondylitis Association, this app makes it easy for patients to record their symptoms, but is quite journal orientated in style. It is also easy for patients to record their fatigue levels and daily mood via unique emojis. Patients can choose what they want to track.



SUAS App

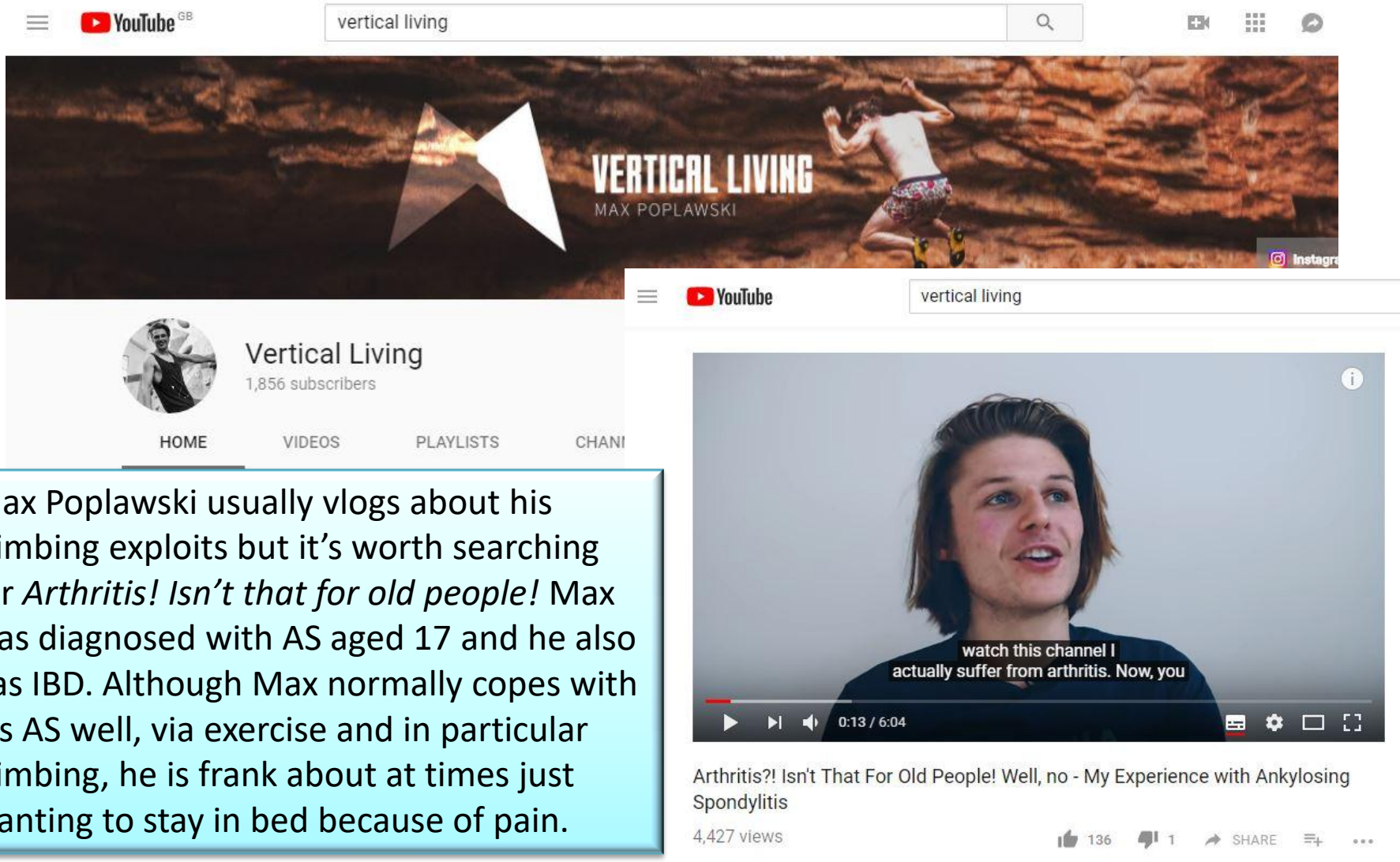
The *SUAS* app (supporting and understanding AS) developed by the AS Association of Ireland in partnership with Waterford Regional Hospital Rheumatology Unit. A little like the Irish AS Association website, this app is quite wordy, and I am not sure if it is still fully operational. I was able to download it earlier this month, however the exercise videos will not play on my iPad.

Nevertheless I decided to still include it because it is the only app that uses the AS Work Instability test and BASFI for monitoring progress, and this may be useful for some patients, and it will still produce a graph over time for monitoring purposes.

Although on the advertising for the *SUAS* app it says it is available from Google play, I could only find it on the App Store.



YouTube Vlogger



vertical living

VERTICAL LIVING
MAX POPLAWSKI

Vertical Living
1,856 subscribers

HOME VIDEOS PLAYLISTS CHANNEL

watch this channel I actually suffer from arthritis. Now, you

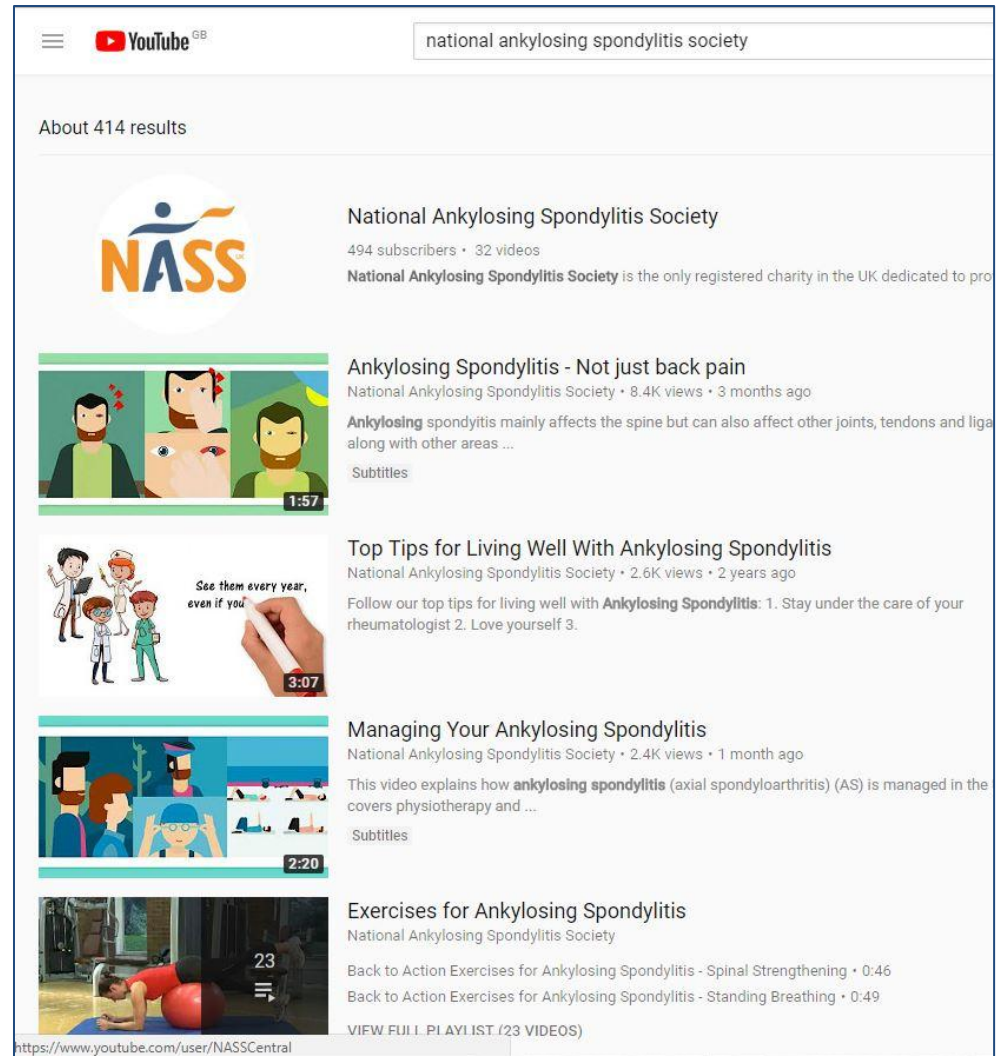
Arthritis?! Isn't That For Old People! Well, no - My Experience with Ankylosing Spondylitis

4,427 views 136 1 SHARE

Max Poplawski usually vlogs about his climbing exploits but it's worth searching for *Arthritis! Isn't that for old people!* Max was diagnosed with AS aged 17 and he also has IBD. Although Max normally copes with his AS well, via exercise and in particular climbing, he is frank about at times just wanting to stay in bed because of pain.

NASS has its own YouTube Channel

NASS have their own YouTube channel with short informative videos, vlogs and the Back To Action exercises.



The screenshot displays the YouTube channel page for the National Ankylosing Spondylitis Society (NASS). The search bar at the top shows the query "national ankylosing spondylitis society" with "GB" next to the YouTube logo. Below the search bar, it indicates "About 414 results".

The channel's profile is shown with the NASS logo, the name "National Ankylosing Spondylitis Society", 494 subscribers, and 32 videos. A description states: "National Ankylosing Spondylitis Society is the only registered charity in the UK dedicated to pro".

Four video results are listed:

- Ankylosing Spondylitis - Not just back pain**
National Ankylosing Spondylitis Society • 8.4K views • 3 months ago
Ankylosing spondylitis mainly affects the spine but can also affect other joints, tendons and ligaments along with other areas ...
Subtitles
- Top Tips for Living Well With Ankylosing Spondylitis**
National Ankylosing Spondylitis Society • 2.6K views • 2 years ago
Follow our top tips for living well with **Ankylosing Spondylitis**: 1. Stay under the care of your rheumatologist 2. Love yourself 3.
- Managing Your Ankylosing Spondylitis**
National Ankylosing Spondylitis Society • 2.4K views • 1 month ago
This video explains how **ankylosing spondylitis** (axial spondyloarthritis) (AS) is managed in the covers physiotherapy and ...
Subtitles
- Exercises for Ankylosing Spondylitis**
National Ankylosing Spondylitis Society
Back to Action Exercises for Ankylosing Spondylitis - Spinal Strengthening • 0:46
Back to Action Exercises for Ankylosing Spondylitis - Standing Breathing • 0:49
VIEW FULL PLAYLIST (23 VIDEOS)

The URL at the bottom is <https://www.youtube.com/user/NASSCentral>.

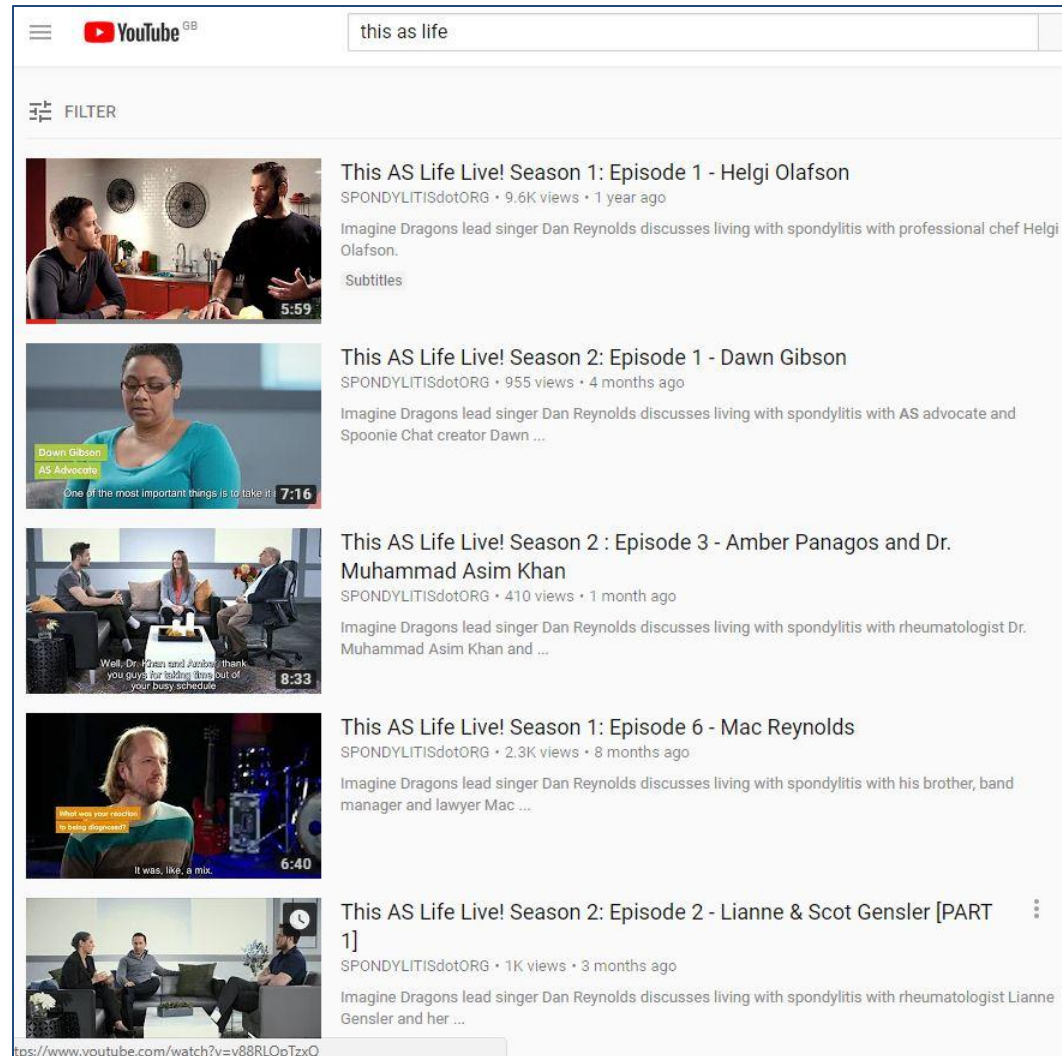
This AS life on YouTube



Which Brings together people with AS to share their stories and inspire each other to live their best lives.

Dan Reynolds from the band Imagine Dragons, who himself has AS, in conversation with.....

A new mum, a student, a chef, a band manager, a writer, a tweeter, a Grandmother, a Rheumatologist amongst others, all have AS, and share their stories in 5-8 minute conversations.



The screenshot shows the YouTube channel 'this as life' with a search bar containing 'this as life'. Below the channel name is a 'FILTER' button. The video list includes:

- This AS Life Live! Season 1: Episode 1 - Helgi Olafson**
SPONDYLITISdotORG • 9.6K views • 1 year ago
Imagine Dragons lead singer Dan Reynolds discusses living with spondylitis with professional chef Helgi Olafson.
Subtitles
- This AS Life Live! Season 2: Episode 1 - Dawn Gibson**
SPONDYLITISdotORG • 955 views • 4 months ago
Imagine Dragons lead singer Dan Reynolds discusses living with spondylitis with AS advocate and Spoonie Chat creator Dawn ...
- This AS Life Live! Season 2 : Episode 3 - Amber Panagos and Dr. Muhammad Asim Khan**
SPONDYLITISdotORG • 410 views • 1 month ago
Imagine Dragons lead singer Dan Reynolds discusses living with spondylitis with rheumatologist Dr. Muhammad Asim Khan and ...
- This AS Life Live! Season 1: Episode 6 - Mac Reynolds**
SPONDYLITISdotORG • 2.3K views • 8 months ago
Imagine Dragons lead singer Dan Reynolds discusses living with spondylitis with his brother, band manager and lawyer Mac ...
- This AS Life Live! Season 2: Episode 2 - Lianne & Scot Gensler [PART 1]**
SPONDYLITISdotORG • 1K views • 3 months ago
Imagine Dragons lead singer Dan Reynolds discusses living with spondylitis with rheumatologist Lianne Gensler and her ...

The URL at the bottom is <https://www.youtube.com/watch?v=v88RLOpTzxQ>.

- These are a few websites, Apps and videos that I have found useful to suggest to a number of of my patients, as appropriate, and I hope some of you may find one or two useful for yours.
- If you know of others that are specifically for patients with AS or Ax SpA that you or your patients have found helpful that you can recommend, then please let us know at comms@astretch.co.uk or astretch@astretch.co.uk and we can add them to our list.
- Please note all of the mentioned websites, apps and YouTube links were correct as of 01/09/2018