



Ankylosing Spondylitis Personalised Care Plan

Claire Jeffries

(Physiotherapy Specialist in Hydrotherapy & Rheumatology)

Colin Beevor

(Matron and Nurse Specialist in Rheumatology)



Presenter Disclosure Information:

Conflicts of interest

The speakers have no conflicts of interest

Session aims

- Introduce the concept of Personalised Care Plans (PCP)
- Discuss the development process undertaken for the AS PCP
- Present the AS PCP

Ankylosing Spondylitis: a long term condition

- 15 million people in England = ≥ 1 long term condition
 - Use 52% of GP appointments
population
 - Use 65% of outpatient appointments
 - Poorer Quality of Life
- account for 31%
of the

Focus on medical needs & treatments

Limited attention on social, psychological & holistic needs

Ankylosing Spondylitis: a long term condition

- 90% of individuals with long term conditions feel comfortable taking responsibility for their own health (1) Ipsos/Mori April 2009
- > 75% LTC patients would feel more confident with self-caring if they had help from a health professional

Limited knowledge of their condition

Limited influence over their care

No plan for managing their condition

The modern NHS – operating framework

Commissioning for Health and Wellbeing:

- More individualised services
- More focus on prevention of disease and complications
- Greater choice – including supporting people to make healthier and more informed choices
- Reducing health inequalities

The demands of
the modern NHS

Empowering patients
with LTC's



NHS

Do you or your child have a long term condition?



Did you know a care plan will help you manage your condition better?



**Your health,
your way,
your choice.**

The image shows a white NHS leaflet. At the top right is the NHS logo. Below it is the question 'Do you or your child have a long term condition?' in pink. Underneath is a cartoon illustration of a family: a young child in a wheelchair, a woman, an elderly woman in a wheelchair, and a man. Below this is another question in pink: 'Did you know a care plan will help you manage your condition better?'. Underneath is a cartoon illustration of three healthcare professionals: a man, a woman, and a man. At the bottom right of the leaflet is a blue box with the text 'Your health, your way, your choice.' in white.

Commitment to Personalised Care Plans

Our Health, Our Care, Our say: (3)

- Commitment to all patients with a LTC being offered a PCP by 2010 should they want one

The Operating Framework for the NHS in England 2009/10: (4)

- “Over the next two years, to ensure that those living with a long term conditions receive a high quality service and help to manage their condition, everyone with a long term condition should be offered a personalised care plan.”

The High Quality Care for All: NHS Next Stage Review Final Report: (2)

- *“Over the next two years, every one of the 15 million people with one or more long term conditions should be offered a personalised care plan, developed, agreed and regularly reviewed with a named lead professional from among the team of staff who help manage their care.”*



What is Personal Care Planning?



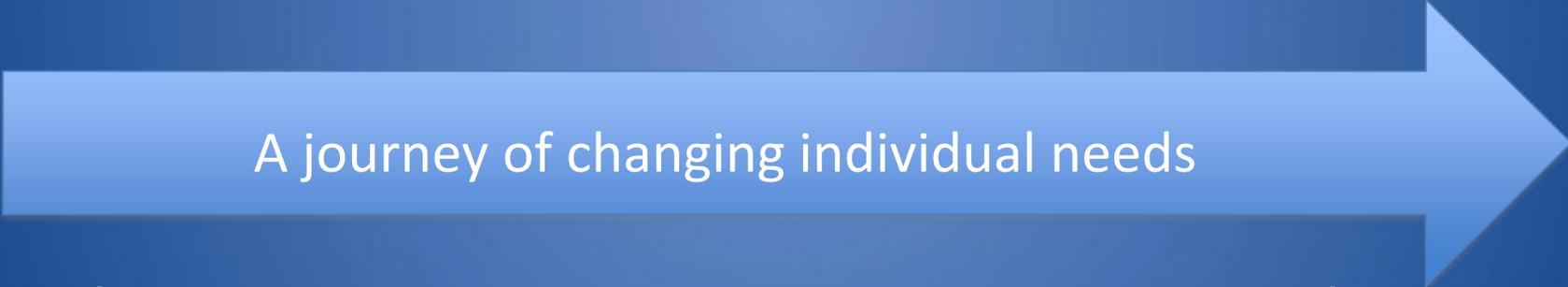
Recognising the impact of non-medical issues

Addressing an individual's full range of needs

Stages in Personalised Care Planning

Stage 1: Newly diagnosed & reassessment

Stage 2: Living with a long Term Condition

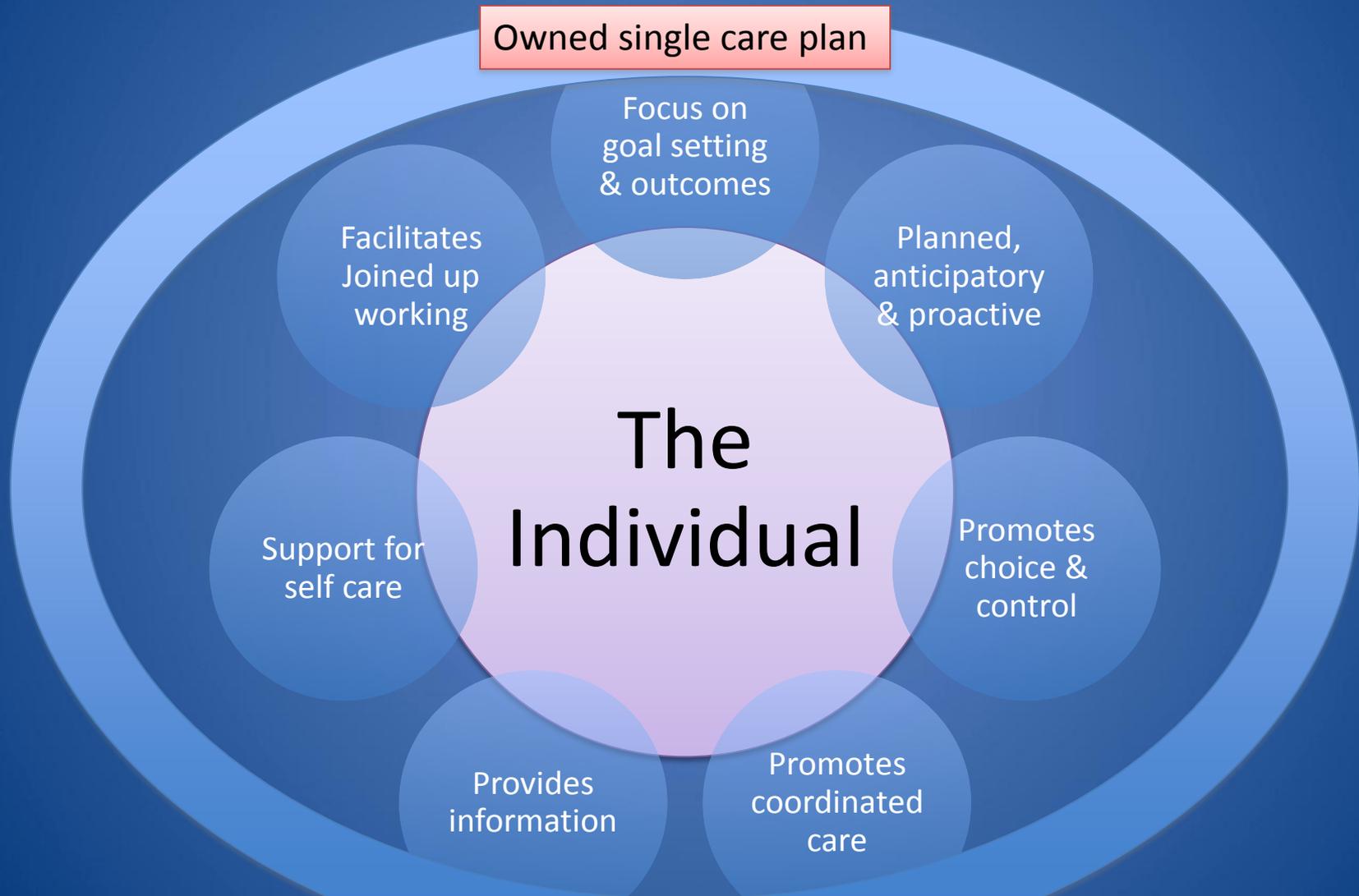


A journey of changing individual needs



shared decision - being given choices & genuine options, becoming empowered

The Care Planning Process – key elements



Expected Benefits – patient ⁽⁵⁾

Sustained health,
independence &
social inclusion

Greater ability to
work

Broader range of
tailored choices

Empowered,
confident to self
manage

Better
management of
medicines & risk

Reduced crisis
episodes

Better long term outcomes

Expected Benefits – service ⁽⁵⁾

Standardised good
quality of care –
improved
outcomes

Better
management of
risk

Reduced GP
appointments <sup>(7
& 8)</sup>

Reduced
unplanned
admissions

Joined up,
coordinated
service

Less duplication of
information service
to patient, patient
to service

Reduction in
complaints

Clinical & cost
effective

Proactive rather than reactive

Individual Personalised Care Plan

- A written (or electronic) record
- Owned (and looked after) by the individual
- For individuals to share with family / carers
- For individuals to share with other health care professionals
- Dynamic / reviewed
- Holistic – seeing the person ‘as a whole’

My Personal Care Plan

Living with Ankylosing Spondylitis

Working in partnership with

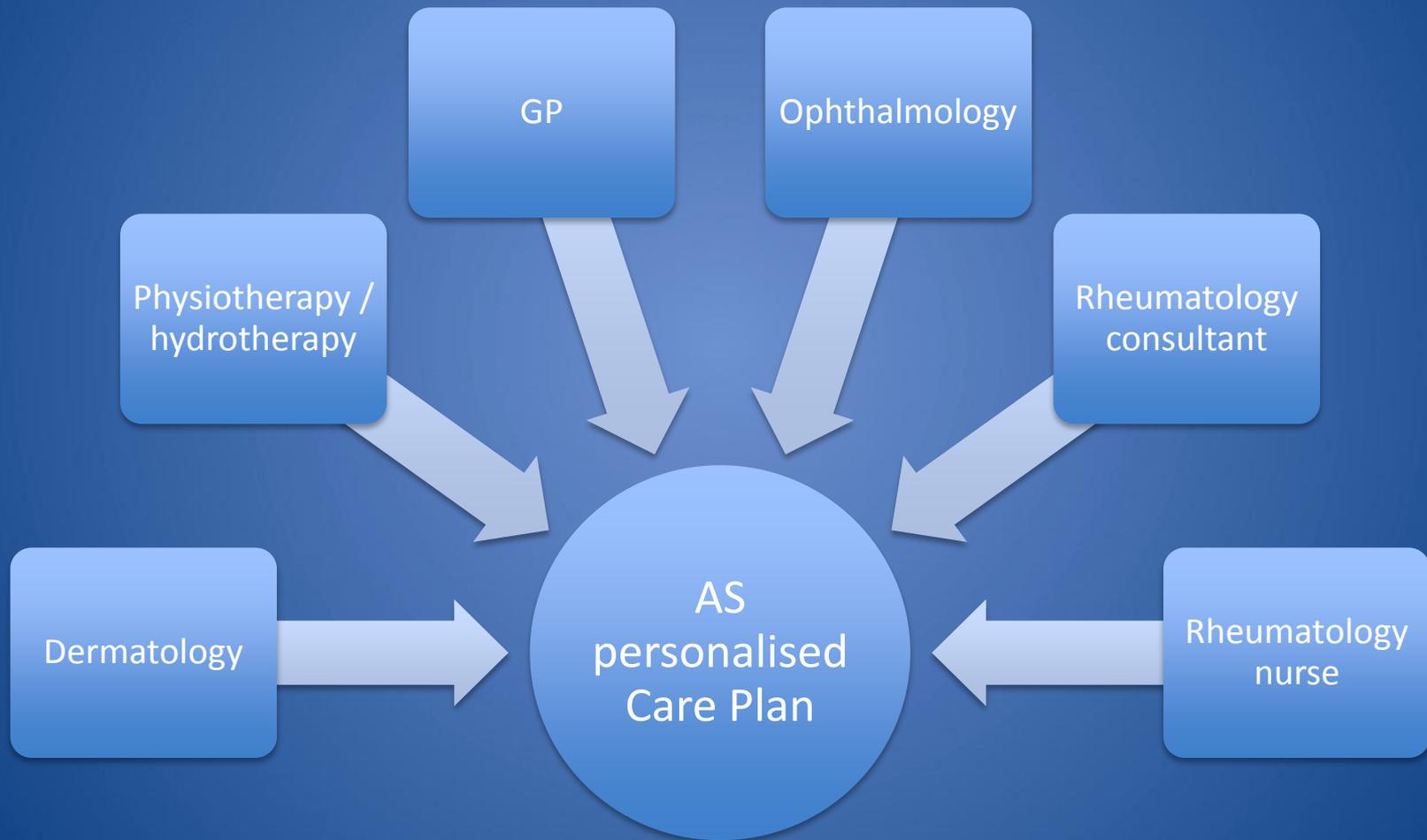
Solent NHS Trust

&

Portsmouth National Ankylosing Spondylitis Society Group



AS Personalised Care Plan



Development of the AS Care Plan

CNS and Physio planning:

Literature, supporting information, format & design

1st draft

Focus group – local AS patients

2nd draft

Peer review: local MDT, Astretch committee, RCN rheumatology forum

Focus group - local AS & NASS group members

3rd draft

NASS head office review

AS care plan launch – Portsmouth November 2012

What is in the AS Individualised Personal Care Plan?

Key facts & self
management
concepts specifically
for AS

Guidance &
management
concepts for
secondary conditions

Exercise principles for
AS and secondary
conditions

Self monitoring
including goal setting

Consultation planning
/ review

Signposting - national
and local resources

What is in the AS Individualised Personal Care Plan?

KEY FACTS:

- The condition
- Associated health conditions / risks
- Exercise management
- Posture management
- Pacing activity
- Pain.....

What is Ankylosing Spondylitis

- An inflammatory condition (that is different to Rheumatoid Arthritis or Osteoarthritis)
- The condition can be seen to have 2 main phases:
 1. Episodes of inflammation where soft tissue (ie: your tendons and ligaments) insert into bone – this occurs mainly at the spine
 2. Extra formation of bone produced at the site where the inflammation occurred
- During a phase of inflammation you may feel pain and fatigue – this can also be referred to as a “flare of your condition”
- Repeated extra bone formation may lead to stiffness in the spine over time as the normal elastic soft tissue is replaced by bone. In some cases the new boney formations can bridge across vertebral bodies (the bones in your spine) causing fusion of the spine.
- People with Ankylosing Spondylitis can experience repeated episodes of inflammation at different sites in the spine (or else where in the body where soft tissue inserts into the bone ie: the heel, breast bone) but it is not yet possible to truly predicated how often or how intense the episodes may be from person to person
- Similarly it is not possible to say if, or to what degree, a person may become stiff in their spine due to extra bone growth

Ankylosing Spondylitis is different to “mechanical low back pain” and different to general wear/tear of the spine that is seen in osteoarthritis

If you are diagnosed with Ankylosing Spondylitis it does not mean that you will become disabled or wheelchair bound

Remember – not all people with Ankylosing Spondylitis have the same level of symptoms – you are all different and individual

Over a course of days, weeks or months it is common for you to have varying levels of pain, fatigue and stiffness



Know your Cardiovascular risk

Research has shown that patients with Ankylosing Spondylitis have an increased risk of developing cardiovascular disease and having incidents such as heart attacks or strokes.

Attending annual cardiovascular risk assessment (with your GP or at your annual Rheumatology review) is important.

As you already have increased risk, reducing all of your cardiovascular risks is essential. The following self management actions need to be considered:

1. Maintaining a healthy blood pressure level
2. Eating a healthy diet
3. Maintaining a healthy weight

4. Exercising regularly to improve your cardiovascular fitness
5. Stopping smoking (if applicable)
6. Controlling / reducing stress levels

Blood Pressure	Cholesterol levels	Smoking	Cardiovascular Exercise
<p>This result tells how hard the heart has to work to move the blood around your body</p> <p>Healthy Range 140/80 or less</p> <p>The following actions can help you to maintain a healthy blood pressure:</p> <ul style="list-style-type: none"> •Regular cardiovascular exercise •Healthy Eating – less salt, less saturated fat, 4-5 portions of fruit and vegetables a day •Limiting alcohol intake: 3-4 units for men and 2-3 units for women per day •Stop smoking 	<p>Raised levels of some lipids (“bad fats”) in the blood are seen in people with Ankylosing Spondylitis.</p> <p>Key actions that you can take to reduce your cholesterol levels include:</p> <ul style="list-style-type: none"> •Eating a healthy diet •Remaining physically fit •Reducing your weight (if you are over weight) •Stopping smoking •Reducing your alcohol intake <p>Assessment of your cholesterol levels should be undertaken by your GP. If you levels are outside of the normal ranges in some cases medications may be prescribed and should be taken in conjunction with the self management actions stated above. Regular review of your cholesterol levels with you GP should be organised.</p>	<p>Smoking increases cardiovascular risk. Smoking when you have Ankylosing Spondylitis can result in worse disease activity, poor functional ability, worse pain and poor quality of life.</p> <p>When giving up smoking people have more success when they use supplementary interventions ie: chewing gum, inhalers, patches or prescribed medicines. This success is enhanced further by accessing a support programme at the same time.</p> <p><u>To help you stop smoking:</u></p> <ul style="list-style-type: none"> •Contact your GP to ask about products to reduce nicotine cravings •Contact sources of support: NHS smoking helpline 08001690169 www.NHS.UK/GOSMOKEFREE 	<p>Current recommendations state that adults should be completing the following level of exercise to maintain a good healthy cardiovascular system ie: efficient working heart and lungs</p> <div style="border: 1px solid blue; padding: 5px; text-align: center; color: red;"> <p>moderately intense exercise</p> <p>30 minutes, 5 times a week</p> </div> <p>Moderately intense exercise means working at a level that makes your heart rate increase slightly or makes you slightly short of breath.</p> <p>Considering your do not want to make any pain from you Ankylosing Spondylitis any worse, some exercises you might consider are: swimming, fast or power walking, cycling, stair climbing</p> <p><u>IF YOU FEEL UNWELL WHISLT EXERCISING - STOP AND SEEK MEDICAL ADVICE</u></p>

Exercise

If I had to choose one exercise ?

SWIMMING

It gives you a good cardiovascular work out, moves your joints and strengthens you all in one exercise. It works you hard without the weight bearing that may irritate your condition when performed to the same level on land

BUT

Good technique is essential to ensure you do not swim with your neck in an extended position

One piece of recommended exercise equipment ?

GYM BALL / FIT BALL

Relatively cheap
Idea for use at home
Can be accessed daily
Can help to move your joints, strengthen, work your postural control / core and stretch you.

Ensure you are measured for the right sized gym ball before you buy it

Always look for “anti-burst” logos before you buy a ball

Can I do “normal” gym and community classes ?

YES!

Classes / exercises to consider:

Yoga
Pilates
Tai chi
Spinning
Water aerobics
Nordic walking
Body balance
Body pump.....

The only sports to avoid are contact sports ie: rugby, kick boxing etc. Some caution should be taken with rackets sports as they involve bending and twisting at speed

What is in the AS Individualised Personal Care Plan?

MONITORING:

- Bath scores
- Blood test results
- Weight
- BP
- Medication
- Exercise regime

Monitoring your Ankylosing Spondylitis

Date & time	BASMI	BASDAI	BASFI	BASG	ASQOL	Work Instability

BASMI – a measure of spinal and hip movement. Scored out of 10. The closer to 10 the more restricted you are due to your condition.

BASDAI - a measure of disease activity. Scored out of 10. The closer to 10 the more active your condition is.

BASFI – a measure of functional ability. Scored out of 10. The closer to 10 the more functionally restricted you are due to your condition.

BASG – a measure of overall coping ability. Scored out of 10. The closer to 10 the greater impact your condition is having on your ability to cope.

ASQOL – a measure of quality of life. Scored out of 18. The closer to 18 the less quality of life you have due to your condition.

Work Instability – a measure to assess your ability to remain at work and be productive at work. Scored out of 20. Scores above 12 may require further investigation or access to support to enable you to remain working.



Monitoring your Ankylosing Spondylitis

Ankylosing Spondylitis Drug:		Start date:
Review date	Dose taken	Overall effectiveness of drug (score 0 – 10) 0 = not effective / 10 = extremely effective
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Monitoring your Ankylosing Spondylitis

Week beginning	Exercise forms completed (walking, yoga class, spinning class, swimming, stretching at home)	Length of time exercise performed	Enjoyment rating (score 0 – 10) 0 = not enjoyable 10 = extremely enjoyable

What is in the AS Individualised Personal Care Plan?

GOAL SETTING:

- Individual to you
- Realistic
- Actions agreed
- Time scales / reviews set

My personal goals

Date	Goal I would like to achieve	What actions am I going to take to achieve it	By when	Achieved date

Local implementation – November 2012

- AS annual review clinics
- AS anti-TNF clinics

Ongoing review of care plans



Which patients would like a care plan ?



How would they like to have their initial care plan discussions???

Ankylosing Spondylitis

Individual Personalised Care Plan

Male

Female

I would be interested in having a Individual Personalised Care Plan Yes No

I would prefer to collect care plan and complete my first Care Planning Discussion:

(please feel free to tick multiple preferences)

- At my next AS clinic appointment
- Via a health professional speed dating event: in the evening during the day
- Via email
- Over the telephone
- A part of the NASS evening group
- Other (please state)

Thank you.

The essence of Personalised Care Planning

Working in partnership

Health professional  Patient

Being informed & taking ownership

Personal reflections

1. Formal way of showing what the majority of Health Professionals in Rheumatology already do
2. Platform for engaging all disciplines in the overall care of a patient
3. Good medium for standardising elements of care even at a local level
4. Really defining the patients goals
5. “yes please / “no thank you”!



Individuals living with long term conditions spend approximately 3 hours every year with healthcare professionals...

for the other 8,757 hours they look after themselves



Thanks

- Local NASS group
 - Chairman
 - Members
- Local Healthcare professionals
 - Dr Young-min
 - CNS Ronnee Bunge-Tuble
- Peer reviewers
 - NASS HQ
 - AStretch
 - RCN rheumatology forum

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