



My details

If this book is found, please return it to:

My diagnosis is:
I also live with these medically diagnosed conditions:
My NHS number is:
My hospital number is:

Note down any questions that you want to ask 20

This book is for you to use to take control of your health and care

Welcome to My plan for my life with



This book is for you to use to take control of your health and care.

We hope it will help you think about what matters most to you and what you want from your care.

You are the expert on how your condition makes you feel. If you can think about what is important to you, you will be able to ask the right questions and get the right information and support.

You can use the book to note down questions that you want to ask and any advice you've had. You can also use it to keep the contact details for the different members of your healthcare team in one place. It has space to record your appointments, test results and discussions too.

Don't feel that you have to fill in every section in this book. It is up to you what you want to record.

If you want, you can bring it with you to your appointments. You can also ask your healthcare professional to write in their comments or advice. It is up to you to decide if you want to share it.

We hope this book will help you to feel more in control of your condition and to be fully involved in planning your care.

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My healthcare team

My healthcare team

This section is for you to record the contact details of the different people in your healthcare team.

Your team will have different skills to help with the different problems you might have. You may not need all of these people on your team. However, if you think that advice or support from one of the specialists below would be helpful, ask your GP or specialist nurse if you can be put in touch with them.

Contact Information

GP name:	
Tel no:	
Email:	
Specialist	nurse name:
Tel no:	
Email:	
Consultan	t / specialist name:
Tel no:	
Email:	
Physiothe	rapist name:
Tel no:	
Email:	

Occupatio Tel no: Email:	onal therapist name:
Podiatrist	name:
Tel no:	
Email:	
Chiroprac	tor name:
Tel no:	
Email:	
Health tra	iner name:
Tel no:	
Email:	
Dietician	name:
Tel no:	
Email:	
Home sur	oport:
Tel no:	
Email:	
Local sup Tel no: Email:	port group name:

Carer support group name: Tel no: Email:
Finance / welfare advisor name: Tel no: Email:
Other useful contacts
Contact name: Tel no: Email:
Contact name:
Tel no:
Email:
Contact name: Tel no: Email:
Contact name:
Tel no:
Email:
Contact name: Tel no: Email:

Understanding my condition

Understanding my condition

Knowing as much as you can about your condition will help you manage living with it better.

There is such a lot of advice and information available that it can be hard to know where to start. There is a list of organisations that can help you at the back of this book. Many have advice and information lines where you can speak to an advisor.

You can share your checklist with your GP or specialist nurse and ask them where you can find more information. Never be afraid to ask questions or for information to be repeated. If you aren't sure what something means then say so.

lf you aren't sure what something means then say so



What would you like to learn more about?

Date:	/	/
Symptoms		
Pain management		
Exercise		
Physiotherapy		
Healthy living (eg. diet, smoking cessation)		
Treatments		
Support at work		
Support at home		
Benefits and financial advice		
Mental wellbeing		
Complementary approaches		
Support groups		
Anything else?		

Date:	/	/
Symptoms		
Pain management		
Exercise		
Physiotherapy		
Healthy living (eg. diet, smoking cessation)		
Treatments		
Support at work		
Support at home		
Benefits and financial advice		
Mental wellbeing		
Complementary approaches		
Support groups		
Anything else?		



Arthritis

Arthritis is a common condition that causes pain and inflammation in the joints. The most common types of arthritis are inflammatory arthritis (IA) and non-inflammatory arthritis (or osteoarthritis). There are many other kinds of rheumatic diseases such as gout, lupus and polymyalgia rheumatica. The sections below provide an overview of the two main types of arthritis, their symptoms and complications and what treatments are available.

> For further information, please consult the links provided at the back of this booklet

Inflammatory arthritis

IA is a term that groups conditions that cause inflammation in joints. When you have some forms of IA, your immune system – which would usually fight infections – attacks your joints by mistake, causing inflammation particularly to the feet, wrists, hands and back. Rheumatoid arthritis, ankylosing spondylitis and psoriatic arthritis are the three most common forms of IA. At present, their causes are unknown, but you are at increased risk of rheumatoid arthritis (RA) for instance, if you smoke, are a woman or have a family history of RA.

Symptoms include pain, stiffness and swelling of the joints and reduced physical strength. Due to the changing nature of the condition, there may be times when your symptoms worsen, known as flare-ups or flares. Although flare-ups are difficult to predict, it is possible to reduce their likelihood and minimise the effect that they can have on your day-to-day life through treatment and life adjustments. It is very important to be diagnosed and treated early to help manage and stop worsening of the condition and to reduce the risk of permanent damage to the joints, and avoid further problems such as inflammation of other areas of the body and even heart attacks and strokes.

Stopping smoking and healthy eating is recommended for everyone

Although there is no permanent cure available for IA, there are several powerful drug treatments that can reduce or even eliminate the symptoms. Alongside medication, physical therapies can also be beneficial in helping you manage your symptoms. These include physiotherapy as well as occupational therapy and hydrotherapy. Exercise is particularly important when you have arthritis as it helps ease the pain, strengthen muscles and stretch joints, help you lose weight if you are overweight and release stress.

Surgery is occasionally needed. This could involve minor surgery such as the release of a nerve or major surgery such as joint replacement. Lifestyle changes can also contribute to help you manage your condition. Stopping smoking and healthy eating is recommended for everyone, but particularly for people with long-term conditions such as IA as a way to help prevent complications.

Osteoarthritis

Osteoarthritis (OA), or non-inflammatory arthritis, causes pain and stiffness to joints and it tends to affect most of us as we get older, but sometimes may affect younger people. Although many joints can be affected, OA seems to most commonly affect knees, hips, neck and back, big toes and hands. This condition occurs when there is damage to the cartilage that covers the ends of bones where they meet to form a joint. It is commonly thought of as 'wear and tear' of joints but the mechanisms are more complicated. Some people have OA in the joints but don't have any pain. However you are more inclined to develop the condition if there is a family history of OA, are over 45 and overweight.

Symptoms can be persistent and include pain and stiffness in the joints along with other symptoms that may affect daily life, including pain and stiffness after sitting still, weakness and muscle wasting.

Simple life adjustments can make a huge contribution to your wellbeing. These include regular exercise including muscle-strengthening exercises, losing weight if you are overweight and using suitable footwear and devices to reduce the strain on your joints. If your symptoms are more severe, medication and a structured exercise plan with the help of a physiotherapist should be introduced in your everyday life. Sometimes, if treatments and life-style adjustments haven't helped or the damage is particularly severe, surgery may also be an option.

Preparing for appointments

Preparing for appointments

Before any appointment, it may be worth thinking about the things you most want to discuss as well as what would be helpful to bring with you.

This could include:

- A list of your medicines (you can use page 60 in this book to create a list)
- Questions for your healthcare professional team (you can find a few suggestions on page 22)
- Any test results (there is a table on page 44 for you to note these)
- Any new health problems that have occurred since your last appointment

(you can also note these down on page 37)

How is my condition affecting me?

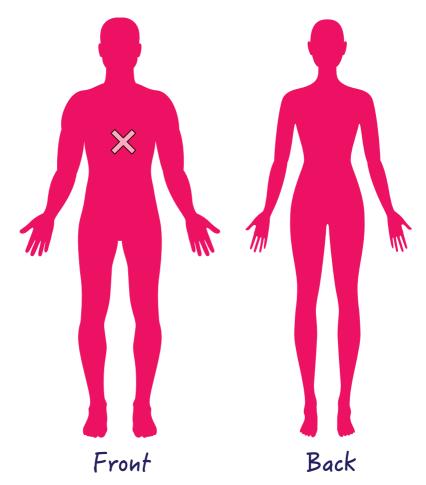
How is my condition affecting me?

Before your appointments it is worth thinking about the effect that your condition is having on you, both physically and emotionally. What symptoms are you experiencing? Has anything changed since your last appointment?

> What symptoms are you experiencing?

Where am I feeling symptoms?

You could use the diagram below to mark where you're experiencing pain or discomfort.



ldentify your levels of pain and fatigue

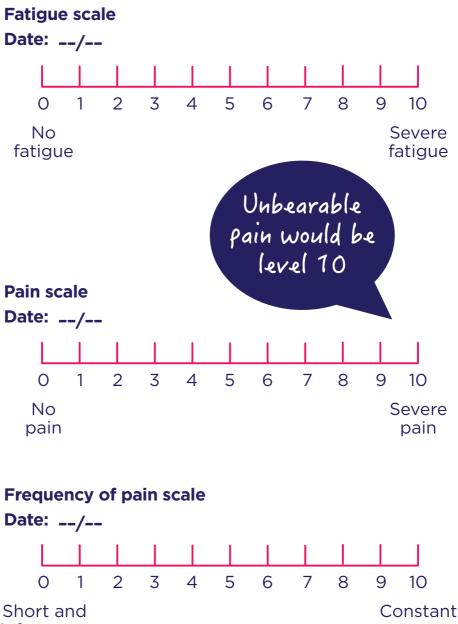
How much fatigue and pain am I feeling?

Scales from one to ten are a good way of monitoring your fatigue and pain levels. To do this, simply decide on the number that best describes your level over the previous week and make a note of it opposite. For example, if your pain levels are unbearable then level ten would best describe that.

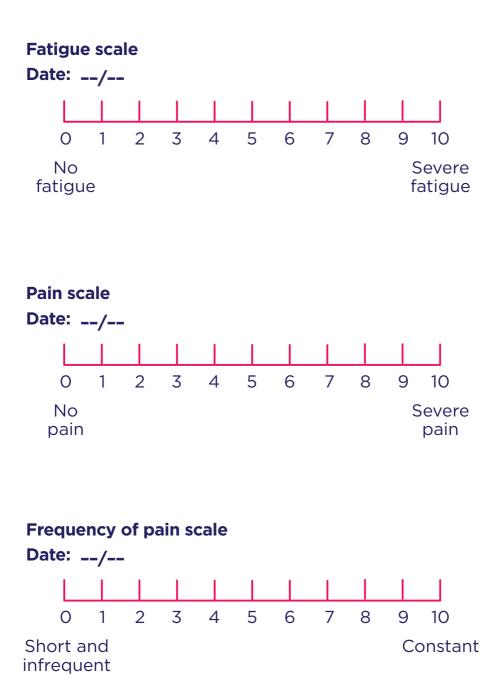
Once you have identified your symptoms and your levels of pain and fatigue, it might help to ask the healthcare professional the following questions:

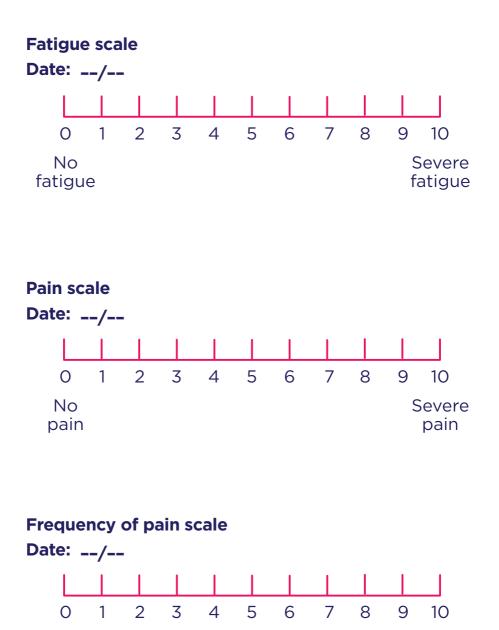
- What is causing my symptoms?
- What can be done to help relieve my symptoms?
- Could changing my medicines improve my symptoms?
- Are there lifestyle changes that I could make that could improve my symptoms?

There are sections later in this book that give more information about medicines and lifestyle changes.



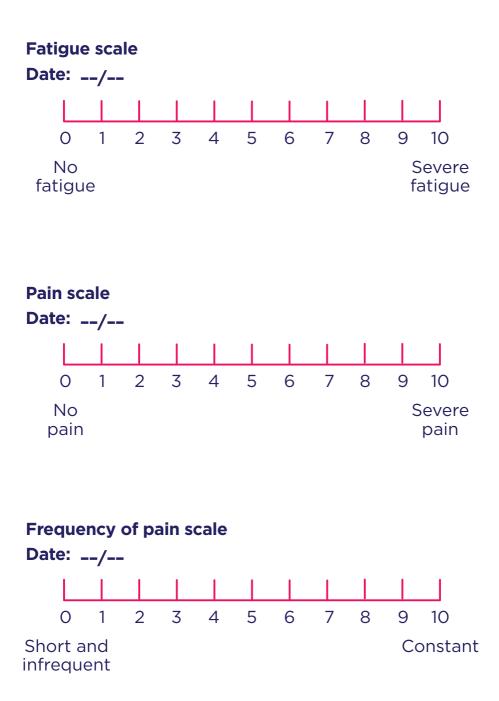
infrequent

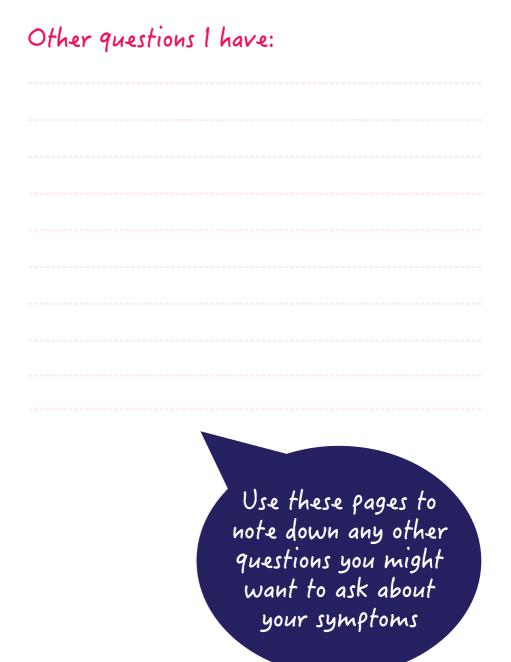




Short and infrequent

Constant





What matters most to me?

What matters most to me?

You're the expert on how your condition makes you feel. If you can think about what is important to you, you'll be able to ask the right questions and get the right information and support.

You can use the space below to write down how your condition affects your life. Think about how you're affected emotionally as well as physically. How are you affected at work and at home, including in your close relationships? Those closest to you may be able to offer their thoughts too.

> You could think about these questions before meeting with your healthcare team

How am I feeling?

How is my condition affecting my life?

What matters most to me right now?

What would I like to change?

What are my goals?

Ask your healthcare team to suggest what you can do and how they can help

What are my goals?

Thinking about what you would like to change, try making a list of your goals. You might want to discuss your goals with those closest to you, and share them with your healthcare team so that they understand what is important to you.

You could also ask your healthcare team to suggest what you can do and how they can help you achieve your goals. Remember, your goals can be both medical as well as personal.

My goal:

How my healthcare team can help:



My appointment tracker

This section is for you to keep a record of your conversations with your healthcare team.

There is space to write questions that you want to ask, the advice you were given and what is happening next (for example a test or a change to your medication).

You can ask your healthcare professional to help you complete this if you want.

Keep a record of your conversations with your healthcare provider

Day of visit: _____ Symptoms since my last appointment: Questions to ask: Advice received: Next steps:

Day of visit:
Symptoms since my last appointment:
Questions to ask:
Advice received:
Next steps:

Day of visit: _____ Symptoms since my last appointment: Questions to ask: Advice received: Next steps:

Day of visit:
Symptoms since my last appointment:
Questions to ask:
Advice received:
Next steps:

Day of visit: _____ Symptoms since my last appointment: Questions to ask: Advice received: Next steps:



My tests

You may find it helpful to use the table overleaf to keep a note of all of your tests, their results and any next steps.

If you aren't sure why you are having a test you should always ask. Your healthcare professional should be able to explain why they are recommending you have a test and what it is for.

They should also be able to tell you how long it will be before your results are ready, as well as explaining what your test results mean and whether anything needs to change.

The majority of blood tests have a range of values which are normal. A consistent upward or downward 'trend' outside the normal range may require action by your doctor or nurse. You can ask your healthcare team to write down any actions required in the table overleaf.

> Keep a note of all your tests, their results and any next steps

Inflammatory arthritis

Date:	/	-	/	/
Haemoglobin				
Platelets				
White blood cells		= ī		
Neutrophils				
Creatinine				
Albumin				
ALT*				
Alkaline phosphatase				
CRP*				
ESR*				
CCP*				
Rheumatoid factor				
Cholesterol				
Disease activity score				
Health Assessment Questionnaire				
Blood pressure				
BASDAI*				
Not all tests will be relevant to your condition, please speak to your healthcare professional if you are unsure about which tests are relevant for you.	* ALT CRP ESR CCP BASDAI	C-reacti Erythro Cyclic c		

Activity Index

tests are relevant for you.

Inflammatory arthritis

Date:	/	/	/
Haemoglobin			
Platelets			
White blood cells			
Neutrophils			
Creatinine			
Albumin			
ALT*			
Alkaline phosphatase			
CRP*			
ESR*			
CCP*			
Rheumatoid factor			
Cholesterol			
Disease activity score			
Health Assessment Questionnaire			
Blood pressure			
BASDAI*			
Not all tests will be relevant to your condition, please speak to your healthcare professional if you are unsure about which	CRP (ESR I	Alanine aminotransfer C-reactive protein Erythrocyte sedimenta Cyclic citrullinated per	ation rate

CCP Cyclic citrullinated peptide antibody BASDAI Bath Ankylosing Spondylitis Disease Activity Index

Inflammatory arthritis

Date:	/	-	/	/
Haemoglobin				
Platelets				
White blood cells				
Neutrophils				
Creatinine				
Albumin				
ALT*				
Alkaline phosphatase				
CRP*				
ESR*				
CCP*				
Rheumatoid factor				
Cholesterol				
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Health Assessment Questionnaire				
Blood pressure				
BASDAI*				
Not all tests will be relevant to your condition, please speak to your healthcare professional if you are unsure about which tests are relevant for you.	* ALT CRP ESR CCP BASDAI	C-react Erythro Cyclic c		

BASDAI Bath Ankylosing Spondylitis Disease Activity Index

tests are relevant for you.

Inflammatory arthritis

Date:	/	/	/
Haemoglobin			
Platelets			
White blood cells			
Neutrophils			
Creatinine			
Albumin			
ALT*			
Alkaline phosphatase			
CRP*			
ESR*			
CCP*			
Rheumatoid factor			
Cholesterol			
Disease activity score			
Health Assessment Questionnaire			
Blood pressure			
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Not all tests will be relevant to your condition, please speak to your healthcare professional if you are unsure about which	CRP (ESR I	Alanine aminotransfer C-reactive protein Erythrocyte sedimenta Cyclic citrullinated per	ation rate

CCP Cyclic citrullinated peptide antibody BASDAI Bath Ankylosing Spondylitis Disease Activity Index

Osteoarthritis

Date:	/	/	/
Haemoglobin			
Platelets			
White blood cells			
Neutrophils			
Creatinine			
Albumin			
Alkaline phosphatase			
CRP*			
ESR*			
Cholesterol			
Blood pressure			

Not all tests will be relevant to your condition, please speak to your healthcare professional if you are unsure about which tests are relevant for you. * CRP ESR C-reactive protein Erythrocyte sedimentation rate

Osteoarthritis

Date:	/	/	/
Haemoglobin			
Platelets			
White blood cells			
Neutrophils			
Creatinine			
Albumin			
Alkaline phosphatase			
CRP*			
ESR*			
Cholesterol			
Blood pressure			

Not all tests will be relevant to your condition, please speak to your healthcare professional if you are unsure about which tests are relevant for you. * CRP C-reactive protein ESR Erythrocyte sedimentation rate

Osteoarthritis

Date:	/	/	/
Haemoglobin			
Platelets			
White blood cells			
Neutrophils			
Creatinine			
Albumin			
Alkaline phosphatase			
CRP*			
ESR*			
Cholesterol			
Blood pressure			

Not all tests will be relevant to your condition, please speak to your healthcare professional if you are unsure about which tests are relevant for you. * CRP ESR C-reactive protein Erythrocyte sedimentation rate

Osteoarthritis

Date:	/	/	/
Haemoglobin			
Platelets			
White blood cells			
Neutrophils			
Creatinine			
Albumin			
Alkaline phosphatase			
CRP*			
ESR*			
Cholesterol			
Blood pressure			

Not all tests will be relevant to your condition, please speak to your healthcare professional if you are unsure about which tests are relevant for you. * CRP C-reactive protein ESR Erythrocyte sedimentation rate

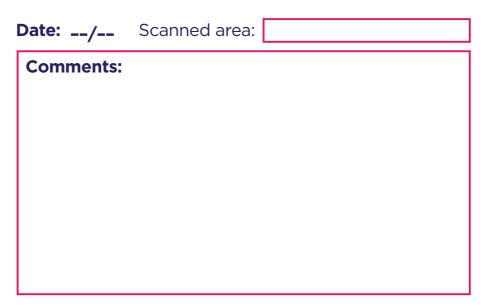
X-rays

Date:/	Scanned area:
Comments:	

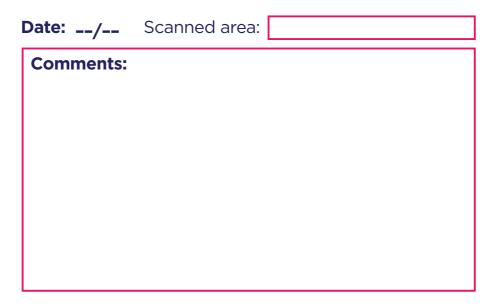
Scans

Date: _	-/	Scanned area:	
Comm	ents:		

X-rays



Scans

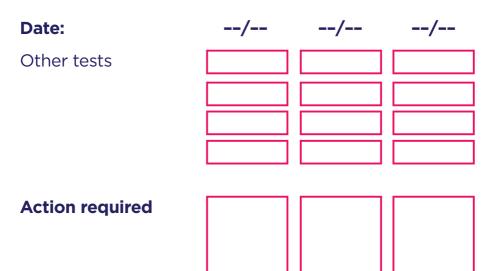


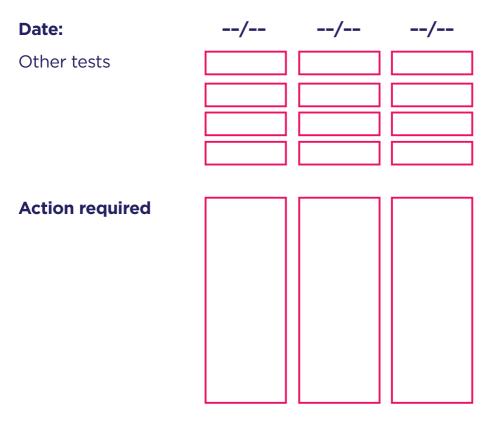
X-rays

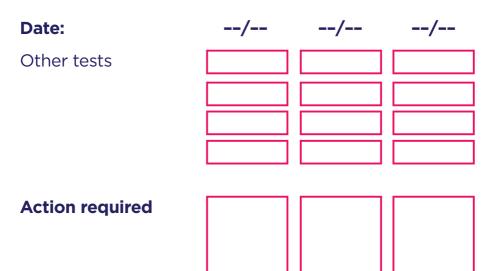
Date:/	Scanned area:
Comments:	

Scans

Date: _	-/	Scanned area:	
Comm	nents:		









My medicines

You may need to take more than one medicine to help manage your condition. You can use this section to make a note of which medicines you are taking, their dosage and how often you need to take them. You can also note down any changes to your medicines and the reasons for them.

It is important that you understand what your medicine is for, how and when you should take it and how it could make you feel. You should feel free to ask any questions you want about any side effects.

It is also important that your healthcare team know if you:

- Have any other conditions for which you take a medicine
- Are taking any regular over-the-counter medicines (eg paracetamol) or herbal or complementary medicines
- Have any allergies

This knowledge will help your team minimise the chances of your different medicines interacting and you experiencing side effects as a result.

Your medicines should be regularly reviewed, to make sure they're still working well for you.

Your healthcare professional should also be able to advise you on how to increase your medication to manage pain. Medicines I take for my musculoskeletal condition:

Medicines I take for other conditions:

Over-the-counter / complementary medicines I take:

My allergies:



My exercise plan

Gentle stretches and exercises can help your joints and muscles feel better. They may also provide pain relief and have long-term benefits for your health.

Your physiotherapist can help you design an exercise plan that is right for you. They may have printed diagrams of exercises you can follow. They may also be able to put you in touch with local groups who run exercise programmes or classes that you could join.

You can ask your physiotherapist to write or draw in the space below their recommendations for the types of stretches and exercises you could be doing.

Exercise suggestions

Exercise can help your joints and muscles feel better

My healthy living plan

My healthy living plan

Eating healthily can help you manage your weight. This will help to reduce the stress put on your joints and muscles as well as having benefits for your overall health and wellbeing.

There are other things you can do to improve your health. For example, if you smoke, quitting is one of the best things you can do for your health.

You can ask your GP or your specialist nurse for advice and support around making changes to your diet or stopping smoking. You could ask them to write in the space below their suggestions for healthy living as well as additional sources of information and support.

Healthy living suggestions

Eating healthily can help you manage your weight

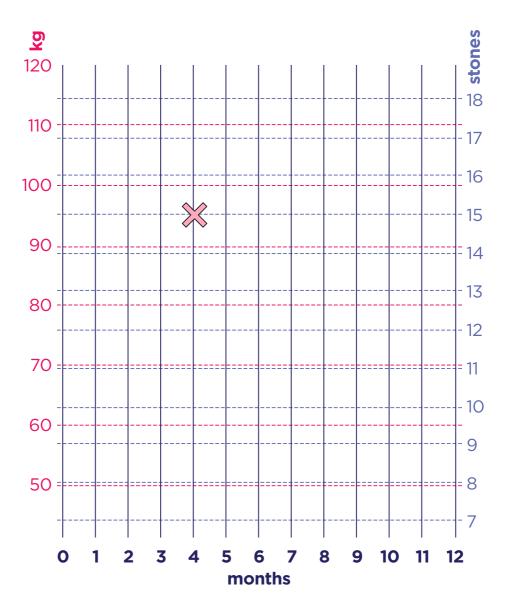


Tracking my weight

You may want to keep track of how your weight is changing, particularly if have agreed with your healthcare professional that it would be good if you could reach a certain weight. It can take time to lose weight. Your healthcare professional will be able to help you work out how quickly it may be realistic to reach your goal weight.

> Use the graph opposite to mark your good weight and plot progress towards it

My goal weight



Tracking my blood pressure

Tracking my blood pressure

If your healthcare professional thinks that it may be helpful to monitor your blood pressure, you can use the following chart to record your readings over time. Your healthcare professional will be able to help you understand what your blood pressure readings mean.



My blood pressure chart



My health and work

My health and work

Work can be important for your health and for your finances. As an employee with a disability you have legal rights and your employer must not discriminate against you. They must also make reasonable adjustments for your condition.

Legally, you don't have to share the details of any health conditions with your employer. However, by being open with them about the kind of support you may need, they will be better able to understand your needs and help you to remain in work.

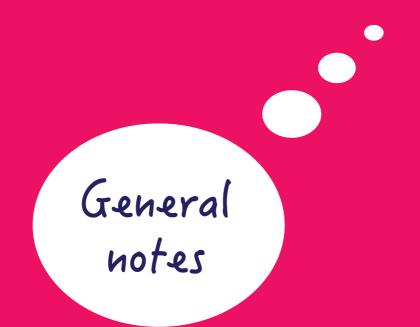
Sometimes your employer may not know how best to help you. Your GP, physiotherapist or an occupational therapist will be able to help you think about how much information about your condition you want to share with your employer, and suggest the sorts of things your employer could do to help you at work.

You can use the section on the page opposite to write down information that you could share with your employer and the ways in which they could help you.

If your condition means that you cannot work, there will be a range of benefits and grants that you may be eligible for. There are some organisations listed at the back of this book that may be able to advise you on money matters.

What do I want to share about my condition?

What sorts of things could my employer do to help?





Where to find more information

The organisations below can provide more information about specific conditions and their treatment, as well as wider information and support. This may be helpful both to you and to any family members or friends who are supporting you. We have also listed sources of information about local NHS services in your area.

England/UK-wide

Age UK

Web: www.ageuk.org.uk Helpline: 0800 169 2081

Arthritis and Musculoskeletal Alliance

Web: www.arma.uk.net

Arthritis Care

Web: www.arthritiscare.org.uk Helpline: 0808 800 4050

Backcare

Web: www.backcare.org.uk

British Society for Rheumatology

Web: www.rheumatology.org.uk

Lupus UK

Web: www.lupusuk.org.uk

National Ankylosing Spondylitis Society

Web: www.nass.co.uk Helpline: 0208 741 1515

National Osteoporosis Society

Web: www.nos.org.uk Helpline: 0808 800 0035

National Rheumatoid Arthritis Society

Web: www.nras.org.uk Helpline: 0800 298 7650

Information about local NHS services NHS Choices

Web: www.nhs.uk

NHS 111 Service - Non-emergency number

Tel: 111

Fit for Work

A Government-funded initiative to support people in work with health conditions and help with sickness absence

Web: www.fitforwork.org Helpline: 0800 032 6235

Scotland

Arthritis Care Scotland

Web: www.arthritiscare.org.uk/scotland Helpline: 0808 800 4050

Information about local NHS services Scotland's Health on the Web

Web: www.show.scot.nhs.uk

NHS 24 - Non-emergency number

Tel: 111

Providing information local to you

Wales

Arthritis Care Wales

Web: www.arthritiscare.org.uk/wales Helpline: 0808 800 4050

Information about local NHS services Health in Wales

Web: www.wales.nhs.uk

NHS Direct Wales - Non-emergency number Tel: 0845 46 47

Northern Ireland

Arthritis Care Northern Ireland

Web: www.arthritiscare.org.uk/northernireland Helpline: 0808 800 4050

Information about local NHS services

Health and Social Care Online

Web: www.hscni.net

GP Out of Hours

Web:	www.gpoutofhours.hscni.net
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Tel: follow the link for a list of local phone numbers

The following organisations can provide information and advice on money matters and benefits: Money matters and benefits advice

England / UK-wide

Citizens Advice

Web: www.citizensadvice.org.uk

Department for Work and Pensions

Web: www.gov.uk/government/organisations/ department-for-work-pensions

Disability Living Allowance

- Tel: 0345 605 6055 (if you were born before 8 April 1948)
- Tel: 0345 712 3456 (if you were born after 1948)

Personal Independence Payment (PIP)

Tel: 0345 850 3322

Scotland

Citizen's Advice Scotland

Web: www.citizensadvice.org.uk/scotland

Wales

Citizens Advice Wales

Web: www.citizensadvice.org.uk/wales

Northern Ireland

Citizens Advice Northern Ireland

Web: www.citizensadvice.co.uk

Department for Social Development

Web: www.dsdni.gov.uk/topics/ benefits-and-pensions



Acknowledgements

This book was created by: Arthritis and Musculoskeletal Alliance, Arthritis Care, Backcare, British Society for Rheumatology, Chartered Society of Physiotherapy, College of Medicine, The Fit for Work UK Coalition, National Ankylosing Spondylitis Society, National Rheumatoid Arthritis Society, Neil Betteridge Associates, Patient Information Forum, Royal College of General Practitioners, and The Work Foundation.

Thank you to all the patients and healthcare professionals who contributed to its development.

If you have any ideas, tips or suggestions as to how this book can be improved, please get in touch with myplanformylifewith@ incisivehealth.com

The "My plan for my life with..." guide has been created by a coalition of organisations working to improve care for people with musculoskeletal conditions. We want this guide to be as helpful as possible. We would therefore be grateful if you could tell us what you think of the guide by completing a short anonymous questionnaire. There are just a few questions, so it should take no more than five minutes of your time.

The questionnaire can be found here: https://www.surveymonkey.co.uk/r/7KBR8RJ

We would be grateful if you could complete the questionnaire by 31 October 2016.





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