

Welcome to
My plan for my life
with



My details

This book belongs to:

.....

If this book is found, please return it to:

.....

.....

My diagnosis is:

I also live with these medically diagnosed conditions:

.....

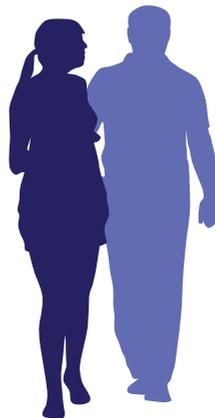
.....

My NHS number is:

My hospital number is:

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.

*Note down any
questions that
you want to ask*



Contents

My healthcare team	4
Understanding my condition	7
Preparing for appointments	10
How is my condition affecting me?	10
What matters most to me?	16
My appointment tracker	20
My tests	25
My medicines	30
My exercise plan	32
My healthy living plan	34
Tracking my weight	36
My health and work	40
General notes	42
Where to find more information	46

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:

Consultant / specialist name:

Tel no:

Email:

Physiotherapist name:

Tel no:

Email:

Occupational therapist name:

Tel no:

Email:

Podiatrist name:

Tel no:

Email:

Health trainer name:

Tel no:

Email:

Dietician name:

Tel no:

Email:

Home support:

Tel no:

Email:

Local support group name:

Tel no:

Email:

Carer support group name:

Tel no:

Email:

Finance / welfare advisor name:

Tel no:

Email:

Other useful contacts

Contact name:

Tel no:

Email:

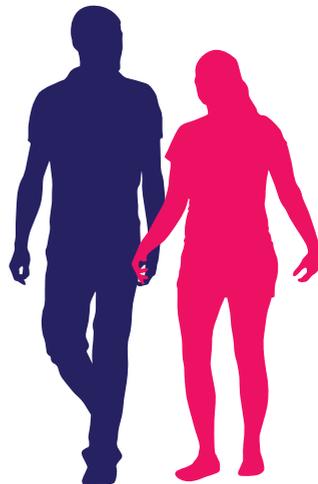
Understanding my condition

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.

*If 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:

--/--

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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?

.....

.....

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:

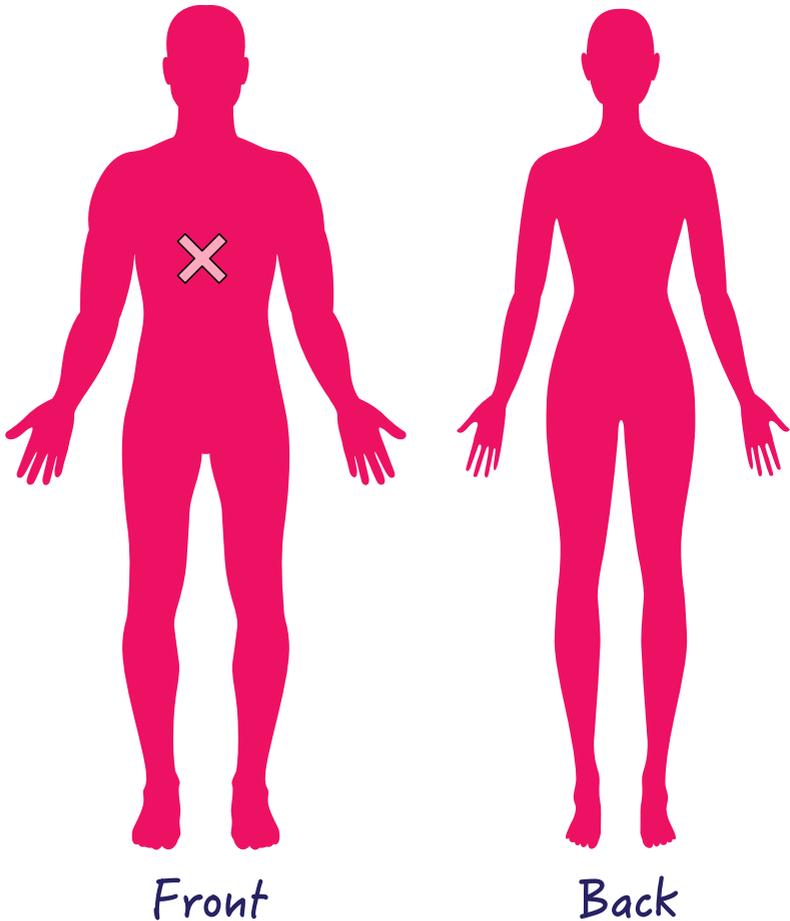
- **A list of your medicines**
(you can use page 30 in this book to create a list)
- **Questions for your healthcare professional team**
(you can find a few suggestions on page 34)
- **Any test results**
(there is a table on page 26 for you to note these)
- **Any new health problems that have occurred since your last appointment**
(you can also note these down on page 20)

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?

Where am I feeling symptoms?

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





Identify your
levels of pain
and fatigue

How much fatigue and pain am I feeling?

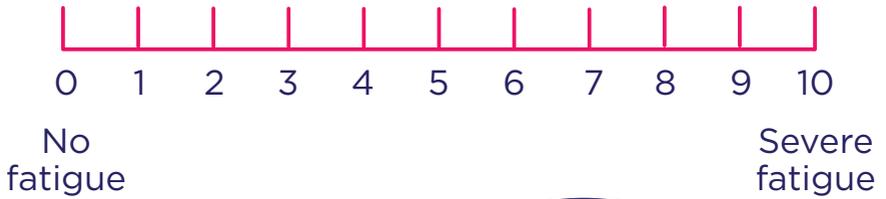
Scales from one to 10 are a good way of monitoring your fatigue and pain levels. To do this, simply decide on the number that best describes your level over the previous week and make a note of it opposite. For example, if your pain levels are unbearable then level 10 would best describe that.

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?**

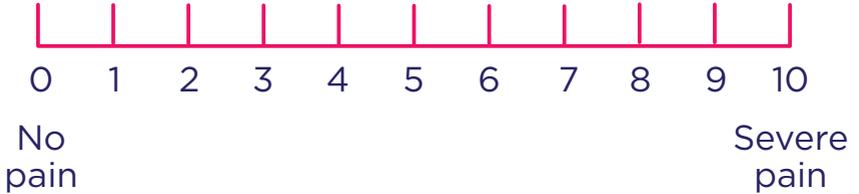
There are sections later in this book that give more information about medicines and lifestyle changes.

Fatigue scale:

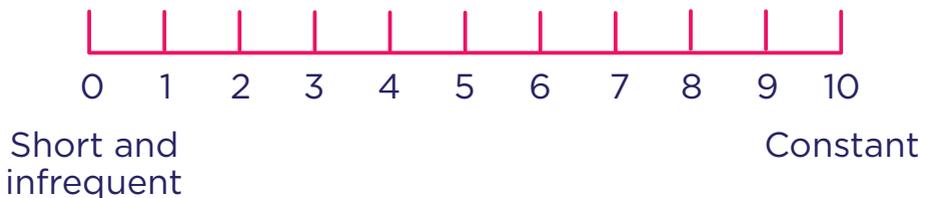


Unbearable pain would be level 10

Pain scale:



Frequency of pain scale:



Other questions I have:

Use these pages to
note down any other
questions you might
want to ask about
your symptoms

A series of 18 horizontal dashed lines, evenly spaced, spanning the width of the page, intended for handwriting practice.

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.



How am I feeling?

How is my condition affecting my life?

What matters most to me right now?

What would I like to change?



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.

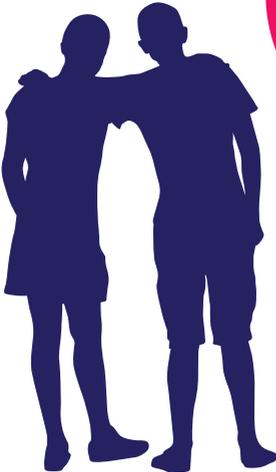
You could also ask your healthcare team to suggest what you can do and how they can help you achieve your goals. Remember, your goals can be both medical as well as personal.

My 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*

My appointments

Day of visit:

Symptoms since my last appointment:

.....
.....
.....

Questions to ask:

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.....
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Advice received:

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Next steps:

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.....
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Day of visit:

Symptoms since my last appointment:

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Questions to ask:

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Advice received:

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Next steps:

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.....
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Day of visit:

Symptoms since my last appointment:

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Symptoms since my last appointment:

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Questions to ask:

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Advice received:

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Next steps:

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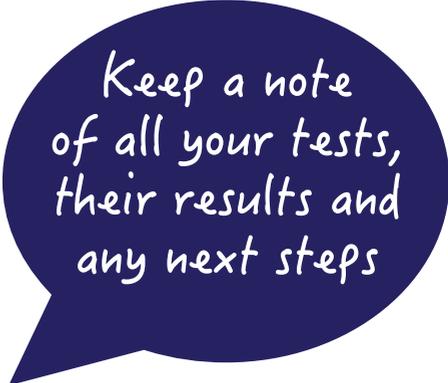
My tests

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 will be 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*

My test results

Date:

--/--

--/--

--/--

Haemoglobin

Mean cell volume

Platelets

White blood cells

Neutrophils

Urea

Creatinine

Albumin

Liver function

Alkaline phosphatase

CRP/ESR*

Cholesterol

Triglycerides

DAS score

Health assessment
questionnaire

Hypertension

X-rays

MRI

BASDAI

BASFI

BASMI

Date:

--/--

--/--

--/--

Haemoglobin

Mean cell volume

Platelets

White blood cells

Neutrophils

Urea

Creatinine

Albumin

Liver function

Alkaline phosphatase

CRP/ESR*

Cholesterol

Triglycerides

DAS score

Health assessment
questionnaire

Hypertension

X-rays

MRI

BASDAI

BASFI

BASMI

My test results

Date:

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--/--

Other tests

Action required

--	--	--

Date:

--/--

--/--

--/--

Other tests

Action required

--	--	--

* CRP = C-Reactive Protein / ESR = Erythrocyte sedimentation rate

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

The page features a series of horizontal dashed lines in a light pink color, spaced evenly down the page. In the lower right quadrant, there is a red speech bubble with a white outline. Inside the bubble, the text "Exercise can help your joints and muscles feel better" is written in a white, cursive font.

Exercise can
help your joints
and muscles
feel better

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

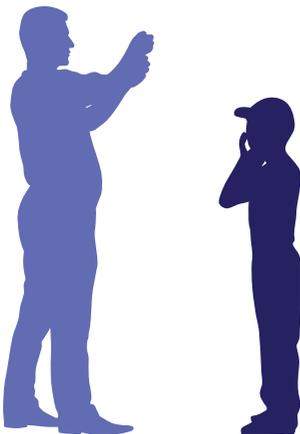
Eating
healthily can
help you manage
your weight

Tracking my weight

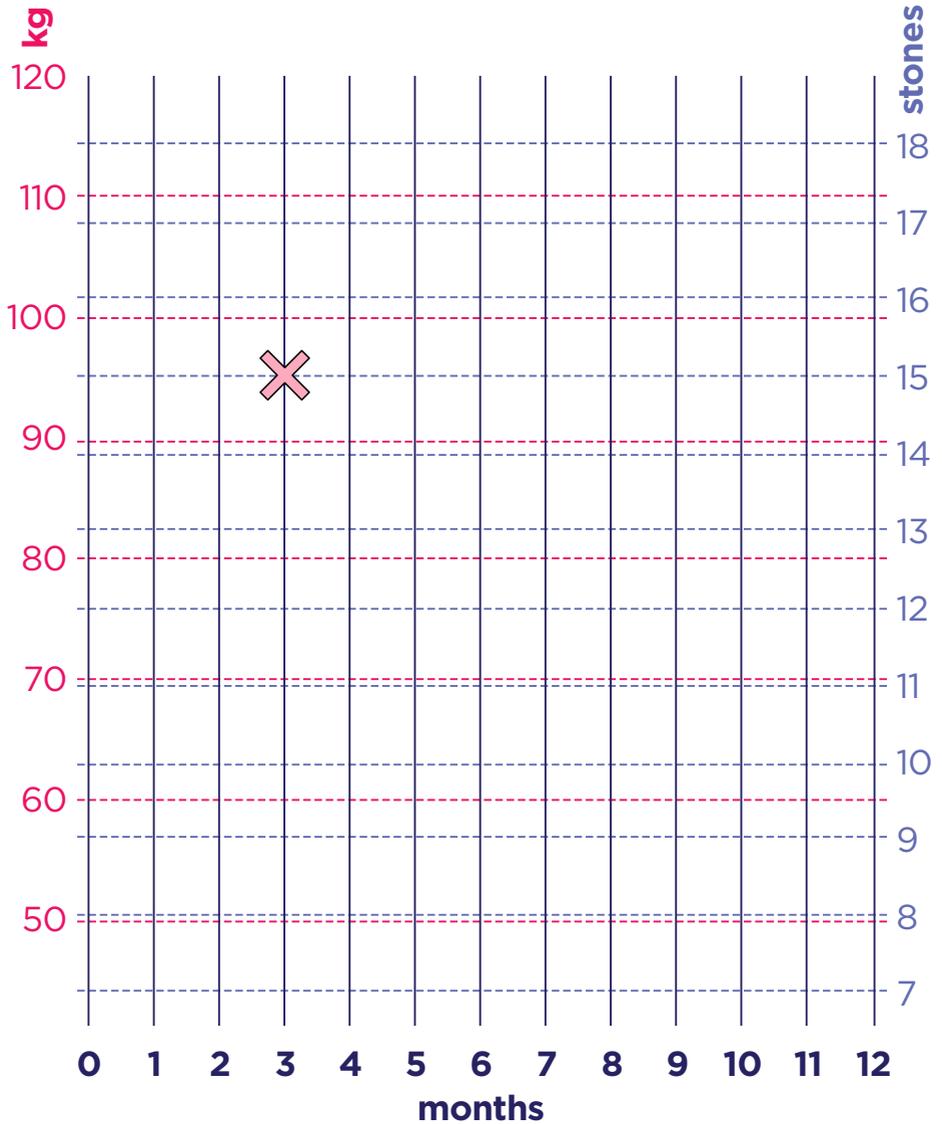
You may want to keep track of how your weight is changing, particularly if you have agreed with your healthcare professional that it would be good if you could reach a certain weight. It can take time to lose weight. Your healthcare professional will be able to help you work out how quickly it may be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



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



My goal weight

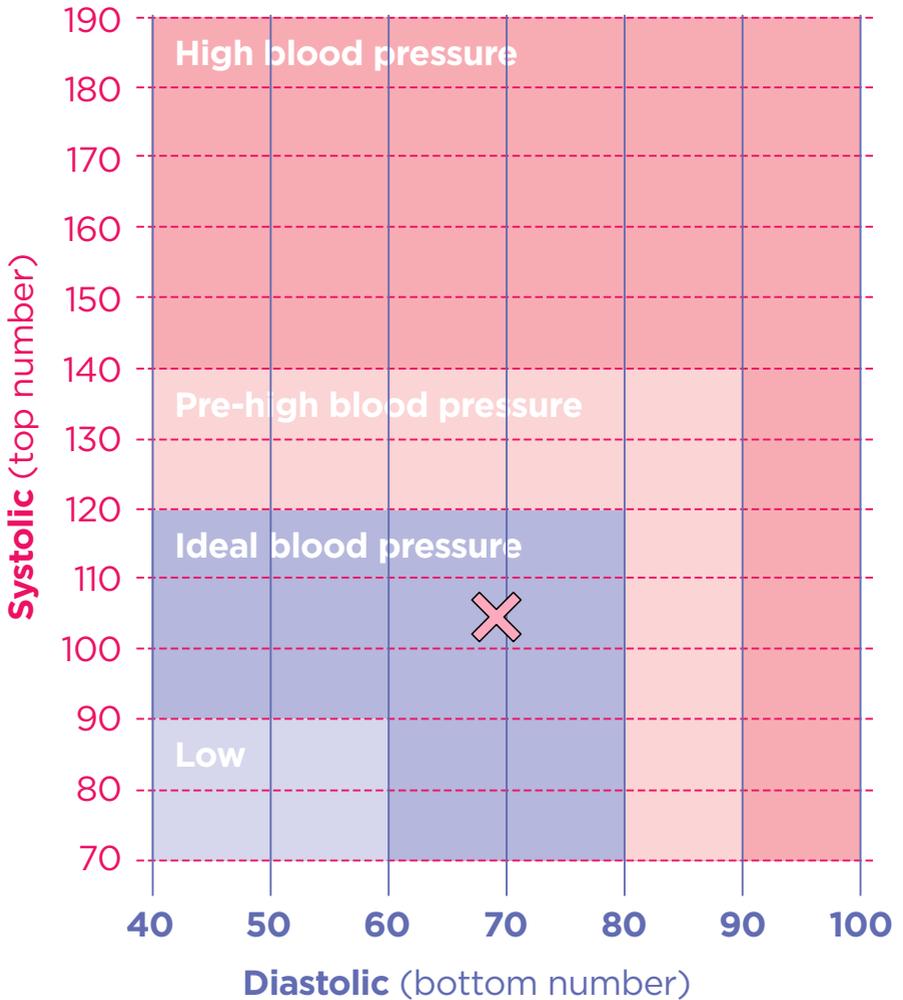


Tracking my blood pressure

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

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.

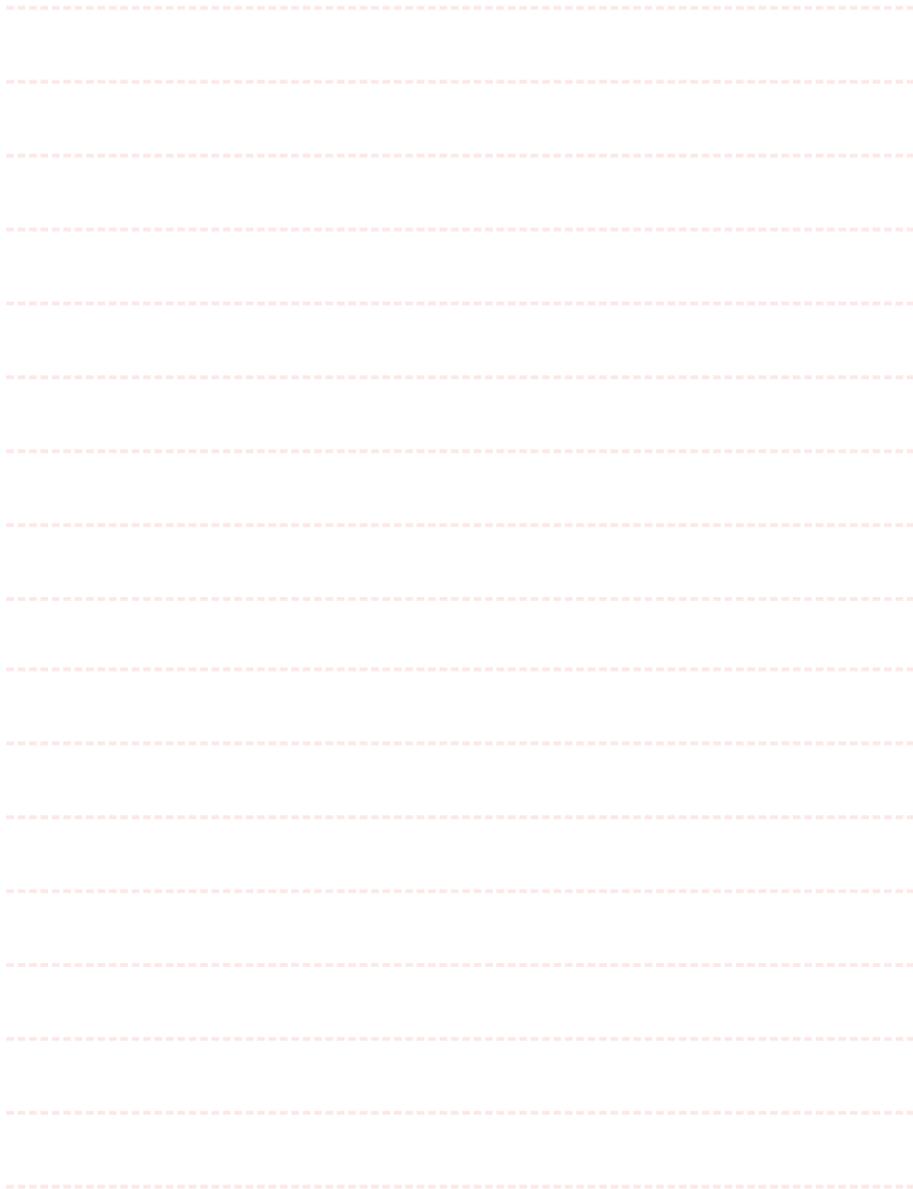
Sometimes your employer may not know how best to help you. Your GP, physiotherapist or an occupational therapist will be able to help you think about how much information about your condition you want to share with your employer, and suggest the sorts of things your employer could do to help you at work.

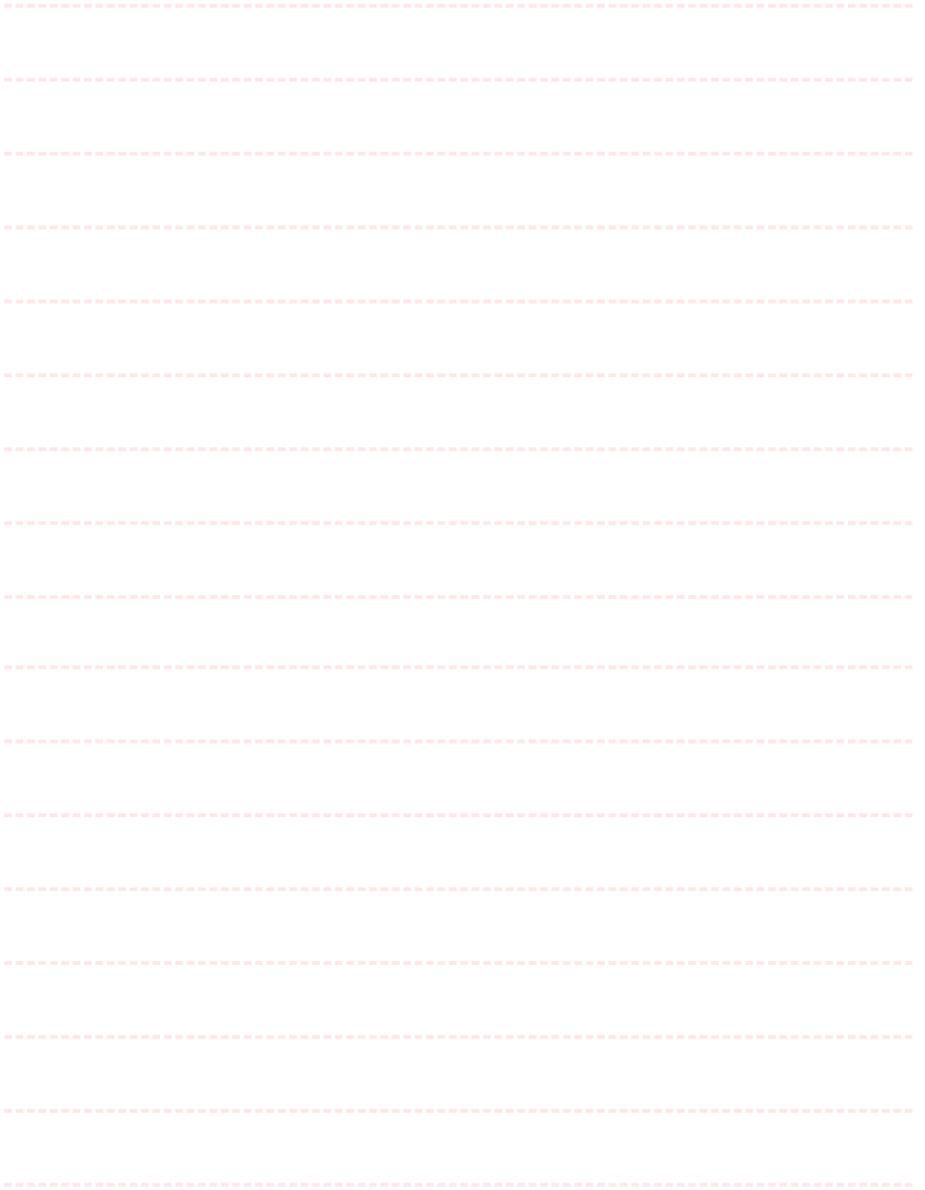
You can use the section on the page opposite to write down information that you could share with your employer and the ways in which they could help you.

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 6565

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: 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/cymru

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

Tel: follow the link for a list of local phone numbers



Money
matters and
benefits
advice

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

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

Benefit Enquiry Line

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

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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](mailto:myplanformylifewith@incisivehealth.com)*

