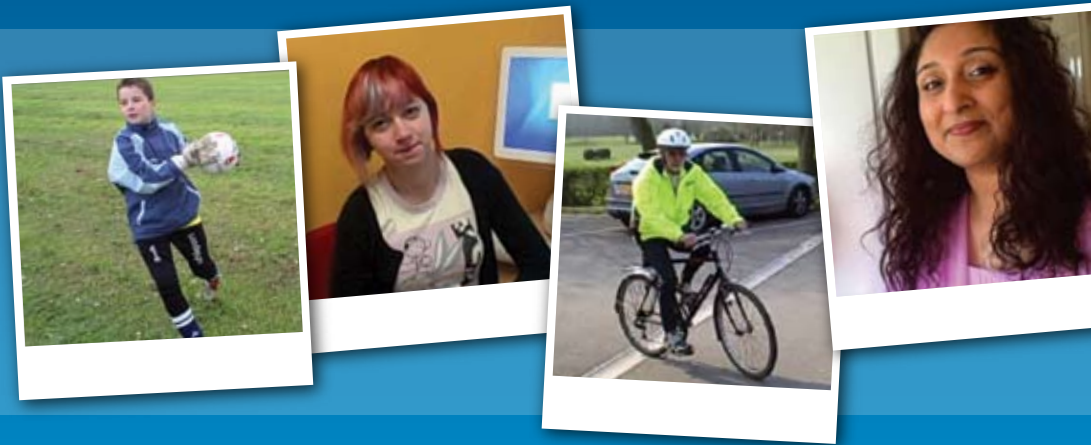


HEALTH PASSPORT NOTES

This health passport has been prepared to A5 size but may be printed to A4 and inserted into a ring binder or stapled into booklet form.



My Health **Passport** to living with arthritis/rheumatism



[LOCAL PATIENT GROUP LOGO]

MY CONTACT DETAILS

THIS PASSPORT BELONGS TO

NAME: _____

ADDRESS: _____

POSTCODE: _____

TEL: _____

EMAIL: _____

IN CASE OF EMERGENCY

NAME: _____

ADDRESS: _____

POSTCODE: _____

TEL: _____

EMAIL: _____

NAME: _____

ADDRESS: _____

POSTCODE: _____

TEL: _____

EMAIL: _____

HEALTH INSURANCE NUMBER

SOCIAL SERVICES NUMBER

MEDICAL NUMBER

MY GP

NAME: _____

ADDRESS: _____

POSTCODE: _____

TEL: _____

EMAIL: _____

MY RHEUMATOLOGIST

NAME: _____

ADDRESS: _____

POSTCODE: _____

TEL: _____

EMAIL: _____

MY OTHER SPECIALIST(S) (e.g. Orthopaedist, Dermatologist)

NAME: _____

TITLE: _____

ADDRESS: _____

POSTCODE: _____

TEL: _____

EMAIL: _____

NAME: _____

TITLE: _____

ADDRESS: _____

POSTCODE: _____

TEL: _____

EMAIL: _____

MY HOSPITAL/MEDICAL CENTRE

NAME: _____

ADDRESS: _____

POSTCODE: _____

TEL: _____

EMAIL: _____

MY SOCIAL CARE

NAME: _____

ADDRESS: _____

POSTCODE: _____

TEL: _____

EMAIL: _____

NAME: _____

ADDRESS: _____

POSTCODE: _____

TEL: _____

EMAIL: _____

MY PATIENT ASSOCIATIONS

NAME: _____

ADDRESS: _____

POSTCODE: _____

TEL: _____

EMAIL: _____

NAME: _____

ADDRESS: _____

POSTCODE: _____

TEL: _____

EMAIL: _____

MY PHARMACIST

NAME: _____

ADDRESS: _____

POSTCODE: _____

TEL: _____

EMAIL: _____

MY OTHER CONTACTS

NAME: _____

TITLE: _____

ADDRESS: _____

POSTCODE: _____

TEL: _____

EMAIL: _____

NAME: _____

TITLE: _____

ADDRESS: _____

POSTCODE: _____

TEL: _____

EMAIL: _____

NAME: _____

TITLE: _____

ADDRESS: _____

POSTCODE: _____

TEL: _____

EMAIL: _____

INTRODUCTION

This health passport has been prepared for people with arthritis/ rheumatism by people with arthritis/rheumatism in Europe* in cooperation with doctors and rheumatologists.⁽¹⁾ We wanted to create something that would make it easy for you to keep a useful record of your health for your own interest and to help you make the most of consultations with your doctor, specialist or other healthcare providers.

Your doctor will want to know about your condition, how it affects what you are able to do and how you are responding to treatments (medications, therapies, supplements, aids and appliances etc.). You may also have questions you want to ask your doctor. These may be small, but important things that are bothering you, which you might forget to ask about when you are with the doctor, or they may be problems you might find it difficult to discuss. There may be some things your doctor or specialist cannot help you with, but he or she may be able to refer you to someone else who can help you.

Your health passport comes in two halves:

The first part of the passport is for you to keep and enter your **personal details, useful contacts** and to record your **long-term medical history**.

Please read this section carefully before filling it in and ask your doctor or specialist to help you complete your medical history to ensure the information is accurate. This will include updating information on **regular or significant** treatments, including new long or short term treatments, or changes to existing treatments, as well as recording any tests you may have.

You will also find a **glossary of terms on page 18** which your doctor may use during your consultation - please let your doctor know if he or she uses any words or terms you do not understand.

⁽¹⁾ PARE Manifesto would like to thank Professor Anthony Woolf for his valuable contribution as medical consultant in the development of this patient passport

*This passport has been developed by People with Arthritis/Rheumatism in Europe (PARE) Manifesto, the campaigning arm of the EULAR (European Leagues Against Rheumatism) Social Leagues, for World Arthritis Day 2007. The theme for World Arthritis Day 2007 is 'small things matter'.

For further information visit www.worldarthritisday.org

To help you prepare for your consultation there is a **list of questions** you might want to ask your doctor when you see him or her.

The second part of the passport is set out as a diary for you to complete on a monthly basis. When you have filled out all the pages, you can apply for a new diary section.

The diary section is designed to help you record:

- how you are feeling
- any changes to your health
- how your health is impacting on your quality of life
- how you are responding to treatments etc.

There are also spaces for you to write notes and to record any temporary treatments you may take for short-term problems that don't affect your long-term condition (see also notes on filling out your diary). These would include occasional medications, such as a course of antibiotics

You will find some pages which have been prepared to help you make **notes for your consultation** at the end of the diary section.

The first page of the consultation notes is for you to complete *before* you see your doctor or specialist. You can use the record you have made in your diary and the list of questions to help you list what you would like to discuss with your doctor or ask about. On the other side of the consultation notes there is a section for you to fill in with your doctor *during* the consultation. This is where you can agree goals and next steps. This page will be a helpful starting point for you and your doctor when you have your next consultation.

MY MEDICAL HISTORY

DIAGNOSIS			
TYPE	WHEN DIAGNOSED	WHERE DIAGNOSED (hospital, clinic etc.)	WHO MADE THE DIAGNOSIS
MUSCULOSKELETAL PROBLEM (arthritis/rheumatism)			
DO YOU HAVE ANY OTHER HEALTH PROBLEMS? e.g. cardiovascular / diabetes			

DIAGNOSIS CONTINUED...

TYPE	WHEN DIAGNOSED	WHERE DIAGNOSED (hospital, clinic etc.)	WHO MADE THE DIAGNOSIS
Have you had any other significant health problems or major operations in the past? <i>Please enter any operations for arthritis/rheumatism on page 13</i>			

ALLERGIES

WHAT PRODUCTS/ FOODS / SUBSTANCES NEED TO BE AVOIDED	ALLERGIC REACTION	WHEN OCCURED

PLEASE NOTE:

Regular medications = medications taken over a certain amount of time / most days of the week. **Prescription medications** which are taken irregularly should also go here. These could include treatment/s for arthritis/rheumatism such as pain relievers and specific treatments e.g. bisphosphonates for osteoporosis / biologicals for RA etc., as well as **non-prescription** medications taken regularly, such as pain relievers, indigestion tablets and supplements (vitamins / herbals etc.). Temporary/short term medications/supplements should be entered in the diary section.

MEDICATIONS

NAME AND DOSAGE	WHAT TAKEN FOR	WHEN STARTED	WHEN STOPPED	WHY STOPPED
PRESCRIPTION MEDICATIONS TAKEN FOR YOUR ARTHRITIS/RHEUMATISM REGULARLY				

MEDICATIONS CONTINUED...

NAME AND DOSAGE	WHAT TAKEN	WHEN STARTED	WHEN STOPPED	WHY STOPPED
PRESCRIPTION MEDICATIONS TAKEN FOR YOUR ARTHRITIS/RHEUMATISM REGULARLY				
NON-PRESCRIPTION MEDICATIONS TAKEN FOR YOUR ARTHRITIS/RHEUMATISM REGULARLY				

MEDICATIONS CONTINUED...

NAME AND DOSAGE	WHAT TAKEN	WHEN STARTED	WHEN STOPPED	WHY STOPPED
PRESCRIPTION MEDICATIONS FOR OTHER CONDITIONS (e.g. blood pressure)				
VACCINES				
NON-PRESCRIPTION MEDICATIONS TAKEN FOR OTHER CONDITIONS (e.g. blood pressure)				
SUPPLEMENTS TAKEN REGULARLY e.g. vitamins, herbal remedies etc.				

OTHER TREATMENTS AND THERAPIES FOR YOUR ARTHRITIS/RHEUMATISM

WHAT	WHEN	WHERE <i>(if appropriate)</i>	HOW DID IT HELP
OPERATIONS/SURGERY FOR ARTHRITIS/RHEUMATISM			
THERAPIES Physiotherapy, hydrotherapy, occupational therapy etc.			

OTHER TREATMENTS AND THERAPIES FOR YOUR ARTHRITIS/RHEUMATISM

WHAT	WHEN	WHERE <i>(If appropriate)</i>	HOW DID IT HELP
COMPLIMENTARY Osteopathy, chiropractic, massage etc			
DEVICES: AIDS AND APPLIANCES TO HELP WITH ACTIVITIES AND PARTICIPATION			

TESTS e.g. blood, urine, x-rays etc.

WHAT TESTS HAVE YOU HAD OVER THE PAST SIX MONTHS?

TEST	DATE	WHERE WAS IT CONDUCTED (hospital, clinic etc.)	RESULT (if known)

TESTS CONTINUED...

PLEASE LIST TESTS CONDUCTED FROM START DATE OF PASSPORT

TEST	DATE	WHERE WAS IT CONDUCTED (hospital, clinic etc.)	RESULT (if known)

TESTS CONTINUED...

PLEASE LIST TESTS CONDUCTED FROM START DATE OF PASSPORT

TEST	DATE	WHERE WAS IT CONDUCTED (hospital, clinic etc.)	RESULT (if known)

TESTS CONTINUED...

PLEASE LIST TESTS CONDUCTED FROM START DATE OF PASSPORT

TEST	DATE	WHERE WAS IT CONDUCTED (hospital, clinic etc.)	RESULT (if known)

TESTS CONTINUED...

PLEASE LIST TESTS CONDUCTED FROM START DATE OF PASSPORT

TEST	DATE	WHERE WAS IT CONDUCTED (hospital, clinic etc.)	RESULT (if known)

GLOSSARY OF MEDICAL TERMS

Aids and appliances	Items to help support joints, to help with dexterity and mobility, e.g. elasticated straps, splints, kitchen implements with special grips, wheelchairs etc.
Ankylosing spondylitis	(AS) - Inflammatory arthritis affecting the spine. Mostly affects younger men
Analgesic	Pain reliever
Arthritis	Condition affecting joints
Arthritis/rheumatism	Term used to cover the more than 200 musculoskeletal conditions
Anti-inflammatory	Drugs used to reduce pain and inflammation
Anti-TNF*	Also known as biologicals (biological response modifier) A new class of treatment that work by blocking the action of TNF (tumour necrosis factor) the molecule responsible for increasing levels of inflammation in people with RA and AS
Atrophy	Wasting of muscle
Bursitis	Inflammation of the protective 'cushions' between joints
Complementary therapies	These include massage, acupuncture, herbal remedies etc., which can offer symptom relief, but not a cure
Corticosteroids*	Drugs used to control inflammation and may have some disease modifying effects
Crepitus	The sound or grating sensation caused by roughened surfaces within a joint
Deformity	Misalignment of two bones / abnormal shape of bones
DMARD*	(Disease modifying anti-rheumatic drugs) Used to treat people with RA and some other rheumatic conditions who have not responded to NSAIDs
Fibromyalgia	Common disorder causing widespread pain, aching and stiffness that affects the muscles, ligaments and tendons, but not the joints
Flare	Period when disease is active

Gout	Condition where crystals build up in the body and cause joints to become very painful
Juvenile idiopathic arthritis	(JIA) - Also referred to as juvenile arthritis. A general term for arthritis affecting children
Immune system	Body's natural defences against disease
Inflammation	The body's response to infection or injury, characterised by redness, heat, swelling, pain and loss of function
Kyphosis	Rounding of the upper spine (hunch back)
Ligament	Fibrous tissue that attaches bones together and supports joints
Lordosis	Forward curvature of the lower spine (sway back)
Lupus	(Systemic lupus erythematosus – SLE) - A condition which affects the body's immune system causing inflammation. Mostly occurs in younger women
Musculoskeletal system	Term describing the muscles, bones, joints, ligaments and connective tissue
Nodule	Small round knotty lump, which may be associated with RA
NSAID*	(non-steroidal anti-inflammatory drugs) - Drugs used to treat both pain and inflammation. COX-2s are a newer type of NSAID
Opium-derived medicines*	The strongest medication used to treat severe uncontrolled pain
Osteoarthritis	(OA) - Wear and tear on joints which may have other predisposing factors such as obesity, past injury and genetics
Osteoporosis	Thinning of bones with an increased risk of fracture
Paracetamol*	A simple pain reliever used to treat mild to moderate arthritis pain
Polymyalgia rheumatica	(PMR) - An inflammatory condition affecting muscles in and around the shoulder and upper arm areas, buttocks and thighs

* All medications may produce side effects. Please ask your doctor.

GLOSSARY OF MEDICAL TERMS continued

Psoriatic arthritis	A form of arthritis that causes inflammation in and around the joints of some people who live with a skin condition called psoriasis
Referred pain	Pain felt in one part of the body, which is not necessarily the area where the pain is originated
Rheumatism	General word describing aches and pains in the musculoskeletal system
Rheumatoid arthritis	(RA) - Inflammatory disease mainly affecting joints and tendons
Scoliosis	Sideways curvature of the spine
Synovitis	Inflammation of the membrane which lubricates joints
Systemic disease	Disease affecting the whole body
Tendon	Part of muscle that attaches to the bone
Tendonitis	Inflammation of a tendon

QUESTIONS YOU MAY WANT TO ASK YOUR DOCTOR

A checklist of suggested questions you *might* want to ask your doctor/specialist at a consultation, e.g.

- What is my condition and how will it develop?
- What sort of improvements can I expect from my treatment/s?
- How long will it take for this treatment to work?
- What kind of outcomes can I expect?
- What are the side effects of this treatment / these treatments?
- If there is no improvement in my condition when taking this medicine, is there an alternative treatment I could try?
- What kind of activities/foods/drinks/other medicines should I avoid when taking this medicine?
- Would physiotherapy/other complimentary therapies be suitable for me?
- Are there any non-prescription medicines that could be helpful in managing my symptoms?
- Will the medicines I'm currently taking (list all of them) react with the medicines you have prescribed?
- Would you recommend exercise? If so, what type?
- Is there anything else I can do?
- Is there anything else I can try?
- Have I got all the information I need?
- Where can I go for more information?

QUESTIONS YOU MAY WANT TO ASK ABOUT YOUR MEDICINES

- What does this medicine do?
- How long will I need to use it?
- How and when should I take it?
- Should I avoid other medicines, drinks, foods or activities when taking this medicine?
- What possible are the possible risks and side effects and what should I do if they happen to me?

My Health Passport Diary

on living with arthritis/rheumatism



[LOCAL PATIENT GROUP LOGO]

FILLING IN YOUR HEALTH DIARY

To help make it easy for you to fill in your health diary we have used symbols with a scale of very good to very bad etc. Next to each symbol there is space to write qualifying comments. For example, you may be feeling much better because you have had a holiday, or be depressed because your dog has died, rather than anything related to your arthritis/ rheumatism. It is helpful to make a short record of these situations to give a context to changes in your physical and emotional health.

At the end of your health diary you will find **consultation notes pages**. The first part of these is for you to complete before you see your doctor. Use your diary pages as a reminder:

You may also want to make a note of what benefits you hope to achieve between consultations. Please discuss with your doctor what you might reasonably expect. For example, you may want to lose weight or take up an activity such as swimming.

If you are newly diagnosed and have not yet been able to think about what you would like to achieve or you did not think about this at your last consultation, please ignore this section.

If you have already completed a diary, please transfer any notes from your last consultation to this section.

BENEFITS YOU SET TO ACHIEVE AT YOUR LAST CONSULTATION	DATE OF LAST CONSULTATION
1.	
2.	
3.	
4.	

DATE:

GENERAL HEALTH

HOW HAVE I BEEN FEELING?

PLEASE TICK FACE OR INDICATE NUMBER FROM SCALE



5 = VERY WELL 1 = VERY UN-WELL

DO I, OR HAVE I HAD ANY SPECIFIC, NEW OR DIFFERENT PROBLEMS?

HOW HAVE I BEEN COPING?

PAIN

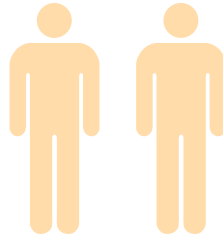
HOW GOOD IS MY PAIN CONTROL?



5 = VERY GOOD 1 = VERY POOR

WHERE DO I HAVE PAIN?

PLEASE CIRCLE AREAS OF PAIN AND INDICATE NUMBER FROM PAIN SCALE



FRONT

BACK

NOTES

HOW MUCH AND HOW OFTEN DO I HAVE PAIN?

Better than usual / the same as usual / more than usual / worse

HOW MUCH DOES IT AFFECT WHAT I CAN DO?

Better than usual / the same as usual / more than usual / worse































DOES IT AFFECT MY SLEEP?

Better than usual / the same as usual / more than usual / worse

OTHER

ACTIVITY AND INDEPENDENCE

IF YOU HAVE DIFFICULTIES IN ANY OF THESE AREAS, TELL YOUR DOCTOR

PLEASE TICK FACE OR INDICATE NUMBER FROM SCALE	5 = VERY EASY – 1 = VERY DIFFICULT	NOTES
SELF CARE / PERSONAL CARE Washing, dressing, going to the toilet, feeding etc.	5  4  3  2  1 	
HOME CARE / DEXTERITY Housekeeping, cooking, shopping, cleaning, laundry etc.	5  4  3  2  1 	
MOBILITY Standing, sitting, walking, climbing stairs, accessing transport etc.	5  4  3  2  1 	
WORK (PAID/UNPAID) EDUCATION (PART TIME/FULL TIME) Reading, typing, using equipment, manual work with tools, heavy work etc.	5  4  3  2  1 	
SOCIAL INTERACTION Relationships, family, friends, looking after children, intimacy etc.	5  4  3  2  1 	
LEISURE Swimming, hiking/walking, playing sports, going out (cinema, restaurants, with friends etc), reading, hobbies, computer etc.	5  4  3  2  1 	
ANY OTHER TASKS I WOULD LIKE HELP WITH?		

MOOD / EMOTIONS

		NOTES
I WOULD DESCRIBE MY MOOD AS? Optimistic, happy, depressed, anxious, afraid, other <i>(Please indicate in box)</i>		ANY PARTICULAR REASON?
PLEASE TICK FACE OR INDICATE NUMBER FROM SCALE	5 = NEVER – 1 = OFTEN	
MY ARTHRITIS AFFECTS MY INTIMATE RELATIONSHIPS	5 😊 4 😊 3 😊 2 😊 1 😞	
MY ARTHRITIS AFFECTS MY RELATIONSHIPS WITH MY FAMILY AND FRIENDS	5 😊 4 😊 3 😊 2 😊 1 😞	
MY ARTHRITIS AFFECTS MY WORK / EDUCATION / RELATIONSHIPS WITH COLLEAGUES	5 😊 4 😊 3 😊 2 😊 1 😞	

TEMPORARY / SHORT-TERM MEDICINES / SUPPLEMENTS

Including herbals, vitamins, changes in diet etc. treatments for flu, hayfever and other short term conditions,

MEDICINES/ SUPPLEMENT	REASON FOR TAKING IT	TAKEN FROM / TO:	HOW DID IT HELP?

CONSULTATION NOTES PAGES

TO BE FILLED IN BEFORE CONSULTATION

DATE OF CONSULTATION:

MY HEALTH

HAVE I HAD ANY DIFFERENT HEALTH CONCERNS SINCE I WAS LAST ASSESSED? Please describe	
HOW HAVE I BEEN COPING? e.g. much better / feeling low	
DO I HAVE ANY SPECIFIC CONCERNS I WOULD LIKE TO DISCUSS?	

TREATMENT REGIMES

HOW HAVE I BEEN GETTING ON WITH ANY MEDICATIONS? please describe	
HAVE I BEEN SATISFIED WITH MY TREATMENTS SINCE MY LAST CONSULTATION?	
HAS THERE BEEN ANY CHANGE TO MY TREATMENT REGIME? e.g. not taking medicines, taking less often, change in time of taking it, going to the physio more or less often etc.	
HAVE I HAD ANY NEW TREATMENTS OR SUPPLEMENTS?	

Wyeth

My Health Passport is a World Arthritis Day project supported by an educational grant from [Wyeth/Country] as part of their Touchpoints programme

