



Striving for the highest level of care

COMPASS

Your guide on your journey
in rheumatoid arthritis

This booklet has been developed by a group of expert rheumatologists and patient representatives, as part of the EVEREST initiative, to help patients with rheumatoid arthritis manage their condition, and does not replace medical examination and/or advice. Please reach out to your healthcare professional if you need any help with managing your rheumatoid arthritis.

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Contents

Introduction	3
Understanding your diagnosis: Be informed	5
Before your visit: Be prepared	7
During your visit: Be involved	8
Between your visits: Stay informed and connected	10
Appendix	
Appendix 1: Basics of RA management	12
Glossary	16



Introduction

You and your healthcare professional are partners on your journey in rheumatoid arthritis (RA), working closely together to ensure the success of this journey.

Through shared decision making, you and your healthcare professional can make decisions together by discussing your preferences and drawing on the clinical knowledge of your rheumatology team.^{1,2} Together, you can develop a treatment plan that works best for you, enabling you to live with RA more easily moving forward.

Throughout your RA journey you will encounter various members of the rheumatology team. Overall this team is often referred to as the multidisciplinary team or MDT. You will work with your healthcare professional (doctor or nurse) to manage your RA. You may also work with other members of this MDT in managing your RA such as physiotherapists and occupational therapists.



Using COMPASS

Similar to how mountaineers prepare for their expeditions, preparation is the foundation of successfully managing your RA. This is especially important because you don't always have a lot of time with your healthcare professional during each visit.

We want to help you to get the most out of your appointments with your healthcare professional, so that you can achieve your clinical goals like remission or low disease activity, or personal goals, like feeling less pain or returning to your way of life before RA.

COMPASS is a guide for people living with RA to read in your own time between visits or at home. It is designed to help you practice shared decision-making with your healthcare professional by:



- Providing **information** about your potential treatment goals and options in RA
- Helping you **prepare** for your visit
- Sharing tips on how you can be more **involved** during your visit
- **Connecting** you to educational resources and support groups

You are invited to review this workbook between visits in your own time and at your own pace.

Understanding your diagnosis: Be informed

Aim high with treat-to-target

The treat-to-target (or T2T) approach was developed to help you achieve your treatment goals in RA and prevent further joint damage.^{3,4} It is based on the following principles:^{2,4}

A. You and your healthcare professional decide on your goal and how to achieve your goal together

B. The most important goal is to maximise your long-term quality of life by:

- Reducing symptoms, such as pain, fatigue, and stiffness
- Preventing damage to the joints
- Regaining physical function and ability to participate in daily activities

C. The most important way to achieve your goal is by stopping joint inflammation

D. By setting a clear treatment target, such as remission, and regularly measuring how active your RA is, you and your healthcare professional can decide how to adjust your treatment if you haven't reached your goal after a certain time.

For a brief refresher on RA please refer to Appendix 1 (page 12)



Set your treatment goals

The primary treatment goal of RA is clinical remission, whenever possible.^{2,4} Remission significantly slows down joint damage and can make your life more enjoyable.⁵ Not everyone living with RA will reach remission. If you have had RA for a long time, low disease activity may be recommended as an alternative goal.



Define your treatment plan

It is important to work with your healthcare professional to develop a treatment plan tailored to you. Your plan may involve prescribed medication(s), lifestyle changes (e.g., healthy diet, physical activity), and complementary therapies.



Track your progress

To help you monitor your progress with treatment, your RA will be regularly assessed using disease activity measures, which include your signs and symptoms of disease, and patient-reported outcomes (PROs), which are your own feedback on how you feel and how well you can do everyday activities. These are usually represented by numbers that reflect how well your RA is being controlled.

Before your visit:

Be prepared



Your consultation time with your healthcare professional may be limited so it is important to prepare beforehand to get the most out of your visits. You are welcome to bring a family member or caregiver with you to your visit if you are comfortable with it.

What to expect at visits

- Your healthcare professional will ask you about your medical history, symptoms, and medications.
- Your healthcare professional may conduct a physical examination and assess your disease activity.
- You will work together to set or revise your treatment.
- You will have the opportunity to ask your healthcare professional questions about your condition, treatment options, and treatment plan.

What to bring to visits

- Name, address, and contact details of your family doctor
- A full list of all of your medications to each appointment (this should include any non-prescription medicines and supplements that you take).
- List of questions or concerns you may have
- Make a note of what your expectations are for the appointment
- A notebook and pen
- If you prefer, a family member or friend to come with you to your consultation



During your visit: Be involved



Get the most from speaking with your healthcare professional

Ask the most important questions first from the list you have prepared before the visit

Do not be afraid to ask your healthcare professional to repeat or explain further if you do not understand

Be open and honest - ask questions and share your concerns clearly

Take notes during your discussion and keep them for reference

Your healthcare professional may use aids to discuss your treatment goals and/or help you choose the best treatment option for you.





Discuss your treatment targets

Discuss what you would like to get from your treatment plan and agree on your short- and long-term treatment goals with your healthcare professional. They will help you identify a clinical goal, which will focus on reducing inflammation, relieving symptoms, and reducing joint damage.

You may also include any personal goals, like getting back to work and returning to a hobby you enjoy, being able to get around independently, thinking about having children, or being able to wear your wedding ring again. This will help your healthcare professional understand what is most important to you when managing your disease as these goals are different for each individual.



Develop your treatment plan

Your healthcare professional will work with you to develop a treatment plan that best suits your individual needs and preferences. These questions may help you decide on a treatment together:

- What are my options?
- What are the pros and cons of these options?
- What does this mean in my situation?

If needed, ask your healthcare professional how much time you have to consider your options. If you don't think your treatment is working well, tell your healthcare professional to find out if a change is needed.

Between your visits: Stay informed and connected

Take control of your RA journey

Your RA journey continues after your visits and the following can make a difference on how quickly you can achieve your treatment targets:

- Taking your treatment on time
- Attending appointments for blood tests and follow-up visits
- Having a healthy lifestyle, such as exercising and eating healthily
- Contacting your healthcare professional if you have any questions or concerns about your treatment (especially if you are experiencing any unexpected side effects). You can also ask for the results of any tests you may have had.
- Talking with your healthcare professional about other health conditions you have that can influence your ability to cope with RA, such as diabetes or heart problems.
- Talking with your healthcare professional about a referral to another allied healthcare professional if needed.

Reach out for support



Family and friends

Your family and friends can offer practical and emotional support in your daily activities. Feel free to invite a family member or caregiver to attend a visit with you or support you with preparing for a visit, as needed.



RA support groups and organisations

You could also consider speaking to others with the same condition via support groups for people with RA, particularly if you find it difficult to share with family and friends.



Online resources

When you are looking for online resources to learn more about RA by yourself, consider the following tips to find information that you can trust:

- Look for websites developed by hospitals or patient organisations, which tend to be more trustworthy than personal websites
- Check when the pages were last updated to find up-to-date information
- Look for evidence, references, and citations (original sources of information) to support the information provided
- Watch out for advertisements that resemble a source of health information
- If needed, compare information from multiple websites



Appendix 1

Basics of RA management

An overview of RA^{2,6}

Your body's immune system protects you against harm from the outside world. Rheumatoid arthritis (RA) is a disease that occurs when your immune system is switched on by mistake.

This causes inflammation in your joints (often in your hands, feet, wrists, elbows, knees, or ankles), leading to pain, swelling, stiffness, and tenderness. It also leads to symptoms outside your joints like fatigue, weight loss, or a low fever.

You should always tell your healthcare professional about your symptoms because:

- Symptoms can vary from person to person and may appear without a pattern
- Your healthcare professional can't see most of these symptoms, so if you don't say how you feel, your healthcare professional won't know how best to treat you
- Symptoms can be a sign that joint damage is happening, so it is important not to wait to say something

It has been shown that smoking may affect the severity of RA. It may also affect how well some medications commonly used to treat the condition work. For these reasons it is advisable that you stop smoking when you have RA.⁷⁻⁹ Information on available assistance to help you to quit smoking can be found in the *further resources* section of this booklet (page 17).

As RA is a chronic (lasting a long time) condition, it can lead to permanent joint damage if it is not well managed. Early diagnosis is very important because studies have shown that delaying treatment can result in more pain and disability in the future.

Summary of T2T recommendations^{2,4}

1. Your **recommended treatment goal** will usually be either clinical remission, which is the absence of signs and symptoms of RA caused by inflammation, or **low disease activity** as an alternative, especially if you have had RA for a long time.
2. Your treatment plan is **based on your treatment goals**.
3. Factors for **treatment decisions** include your disease activity, how much joint damage you have, how well you function in daily activities, and your individual situation (e.g., if you have other diseases, if you have drug-related safety risks, and your personal preferences).
4. You and your healthcare professional should **decide together** on what your treatment goals are and how to reach them.



Appendix 1

Basics of RA management (continued)

Tracking disease control²

Disease activity is a term healthcare professionals use to describe your current level of inflammation, signs (swelling, for example), and symptoms (pain, for example).

The most common ways of measuring your RA disease activity are:

- **CDAI**
Clinical Disease Activity Index
- **SDAI**
Simple Disease Activity Index
- **DAS28**
Disease Activity Score in 28 joints

These are represented by a single number and are based on a combination of some or all of the following:

- Joint examination by your healthcare professional
- How controlled you think your RA is on a scale of 1 to 10 (where 10 is the worst)
- How controlled your healthcare professional thinks your RA is on a scale of 1 to 10 (where 10 is the worst)
- Blood tests



By tracking your disease score over time, your healthcare professional will be able to evaluate how effective your current treatment is.

		How do my numbers correspond to my disease activity? ²			
How is it measured					
	CDAI	≤ 2.8	>2.8-10	>10-22	>22
	SDAI	≤ 3.3	>3.3-11	>11-26	>26
	DAS28	<2.6	≥ 2.6-3.2	>3.2-5.1	>5.1
What does it mean?		REMISSION	LOW	MODERATE	HIGH
	Inflammation	None	Reduced	Present	High
	Symptoms	Absent	Weak	Strong	Severe
	Physical function	Good	Improved	Limited	Poor
	Progression of joint damage	None	Limited	Present	Often

< less than ≤ less than or equal to
> more than ≥ more than or equal to

Glossary

Keywords for managing your rheumatoid arthritis

- **Clinical remission or Remission:** The absence of signs and symptoms of RA caused by inflammation
- **Comorbidities:** Other long-term conditions or diseases that a person with RA may have; for example, diabetes or high blood pressure
- **Disease activity:** Signs and symptoms caused by inflammation due to RA. It is usually categorised as four levels: high, moderate, low, and remission
- **Disease activity measures:** How RA disease activity is measured, based on a combination of information collected from joint examinations, blood tests, and patient feedback; and usually represented by a number
- **Inflammation:** What happens when your immune system is switched on; this leads to pain, swelling, stiffness, and loss of function in the joints, as well as fatigue in RA
- **Patient-reported outcomes or PROs:** Patients' assessments, in their own words, of how they feel and how well they can do everyday activities
- **Rheumatoid arthritis or RA:** A condition that occurs when the immune system is switched on by mistake, leading to inflammation that causes pain, swelling, stiffness, and loss of function in the joints, as well as fatigue
- **Signs:** Features that can be seen by physical examination, such as the number of swollen joints
- **Shared decision-making:** The process during which you and your healthcare professional make treatment decisions together:
 1. Your healthcare professional presents your options with their pros and cons;
 2. You share your thoughts about the different options;
 3. Together, you decide on the option that best fits with your preferences

- **Symptoms:** Features of the disease as experienced by the patient, such as pain, fatigue, and stiffness
- **Treat-to-target or T2T:** Treating your RA until you achieve the lowest levels of disease activity (remission or low disease activity) and maintaining your RA at the same level once this is achieved

Further resources

For more information about arthritis and the range of supports and services that Arthritis Ireland provide visit **www.arthritisireland.ie**.

The Arthritis Ireland helpline is available from Monday to Friday, 10am-4pm. Call **0818 252 846** or email **helpline@arthritisireland.ie** to arrange a callback.

For further information on stopping smoking and to see the range of services offered by the **Health Service Executive (HSE)** to help you quit please visit **www.quit.ie** or freephone **1800 201 203**.

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