

Patient Perspective

SHARING SOME REFLECTIONS ON LIVING WITH A RHEUMATIC AND
MUSCULOSKELETAL DISEASE

Liga Portuguesa Contra as Doenças Reumáticas

Content

PUZZLE

PERSONAL STORY

COLECTIVE EXPERIENCE

Puzzle

Brief knowledge check on
myths & facts around
rheumatic and
musculoskeletal diseases



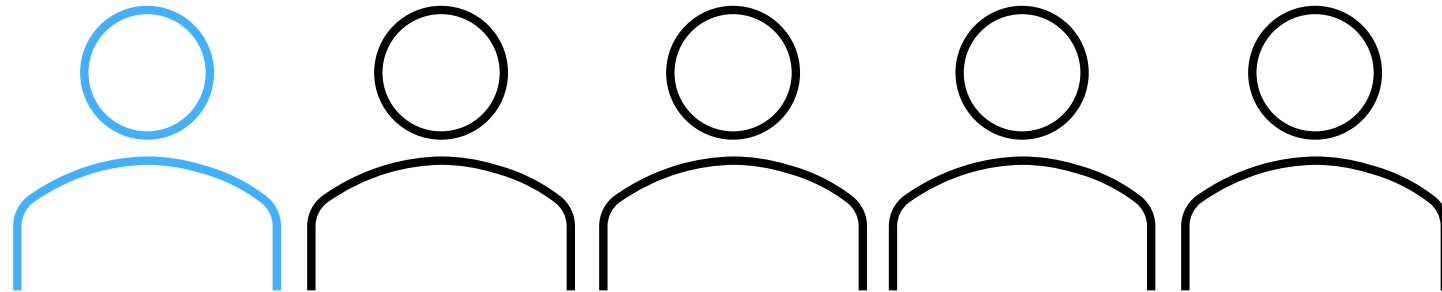
Q1

HOW MANY RHEUMATIC AND
MUSCULOSKELETAL DISEASES
ARE THERE?

a) <100

b) >200

THERE ARE **OVER 200 RHEUMATIC AND MUSCULOSKELETAL DISEASES**
(RMDS)
AFFECTING **~120 MILLION EUROPEANS**



1/5 EUROPEANS LIVE WITH SOME TYPE OF RMD

Q2

RMDs AFFECT ONLY THE WRIST,
ANKLE, AND KNEE JOINTS.

- a) True
- b) False

COMMONLY AFFECT THE MUSCULOSKELETAL SYSTEM (JOINTS OR SPINE, TENDONS AND MUSCLES),
BUT CAN ALSO AFFECT MULTIPLE ORGANS OF THE BODY, INCLUDING THE LUNGS, HEART, KIDNEYS, LIVER, SKIN, AND NERVOUS SYSTEM.
RMDs CAN CAUSE **INFLAMMATION, TISSUE DEGENERATION, AND AUTOIMMUNE DYSFUNCTION.**

Q3

WHAT IS THE PERCENTAGE OF YEARS LIVED WITH DISABILITIES (YLDs) IN EUROPE ACCOUNTABLE TO RMDs?

a) ~30%

b) >50%

RMDs ARE ASSOCIATED WITH **DISABILITY**, THE DEVELOPMENT OF **COMORBIDITIES**, AND **EARLY MORTALITY**.

RMDs ARE THE LARGEST CAUSE OF PHYSICAL DISABILITY IN THE EU, ACCOUNTING FOR **OVER 50% OF YEARS LIVED WITH DISABILITIES** (YLDs) IN EUROPE.

RMD-DRIVEN INFLAMMATION ALSO CONTRIBUTES DIRECTLY TO THE DEVELOPMENT OF **HIGH-MORTALITY NCDS**, INCLUDING CANCER, CARDIOVASCULAR DISEASE, DIABETES, AND MENTAL HEALTH PROBLEMS.

Q4

AFTER RECEIVING A DIAGNOSIS,
THERE IS NOTHING YOU CAN DO.

- a) True
- b) False

LIFESTYLE MEASURES - MAINTAINING A MODERATE WEIGHT, EXERCISING, QUITTING SMOKING, EATING A HEALTHY DIET, AND GETTING ENOUGH SLEEP - CAN SLOW THE PROGRESSION OF SOME TYPES OF RMDs.

MEDICATIONS ARE AVAILABLE THAT CAN HELP REDUCE THE SYMPTOMS OF MANY RMDs AND SLOW DISEASE PROGRESSION.

THE INTRODUCTION OF **BIOLOGICS AND JANUS KINASE INHIBITORS** ALONGSIDE NEW MULTIDISCIPLINARY TREATMENT MODELS HAS BEEN A **GAME CHANGER** FOR MANY PEOPLE WITH RMDs.

Q5

ONLY OLDER ADULTS DEVELOP
RMDs.

- a) True
- b) False

SOME RMDs (OSTEOARTHRITIS, OSTEOPOROSIS) DO OCCUR WITH INCREASING FREQUENCY LATER IN LIFE.

RMDs OCCUR AT ALL AGES, INCLUDING IN CHILDREN, ADOLESCENTS AND YOUNG ADULTS.

TREATMENT THAT IS STARTED EARLY ON IN THE DISEASE PROCESS CAN HELP MINIMIZE OR SLOW DAMAGE TO THE JOINTS AND IMPROVE QUALITY OF LIFE FOR PATIENTS.

References:

<https://www.eular.org/eular-manifesto>

<https://www.urmc.rochester.edu/encyclopedia/>

<https://www.healthline.com/health/rheumatic-diseases#bottom-line>

<https://www.stanfordchildrens.org/>

https://www.medicinenet.com/rheumatoid_arthritis_quiz/quiz.htm

<https://www.medicalnewstoday.com/articles/medical-myths-all-about-arthritis?>

<https://www.webmd.com/rheumatoid-arthritis/rm-quiz-biologics>

Q6

ELSA MATEUS WAS DIAGNOSED WITH A RMD IN:

- a) 1977
- b) 1987
- c) 1997
- d) 2007
- e) 2017

Personal Story

Experiential knowledge

MANY PATIENTS WHO LIVE WITH CHRONIC DISEASES DESCRIBE THEIR LIVES AS A PLAY IN TWO ACTS.

IN THE FIRST ACT, THEY LIVE AS 'NORMAL' HEALTHY PEOPLE.

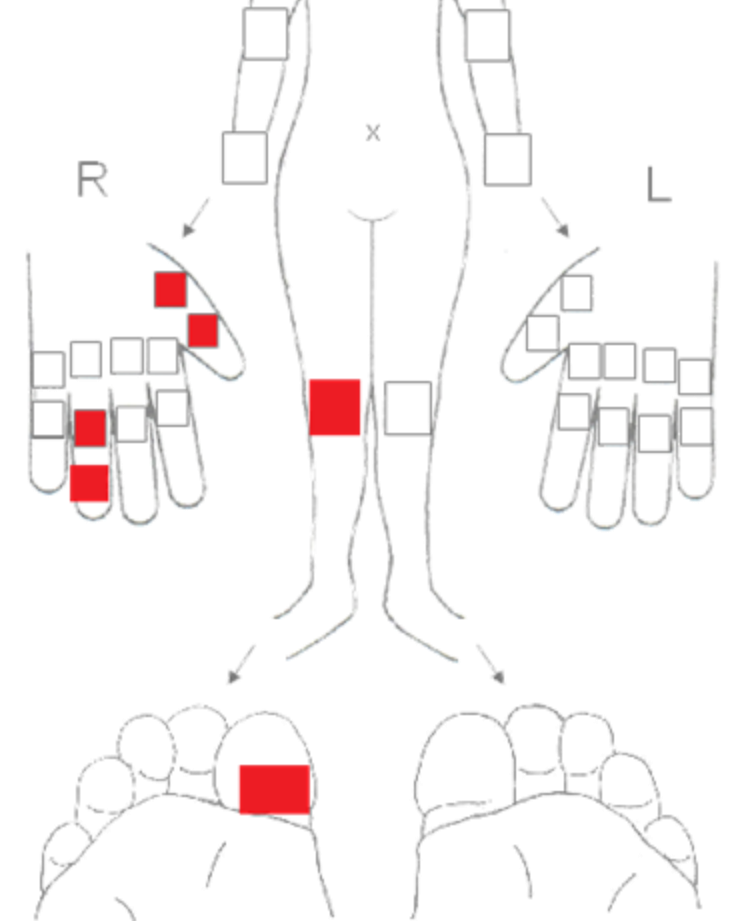
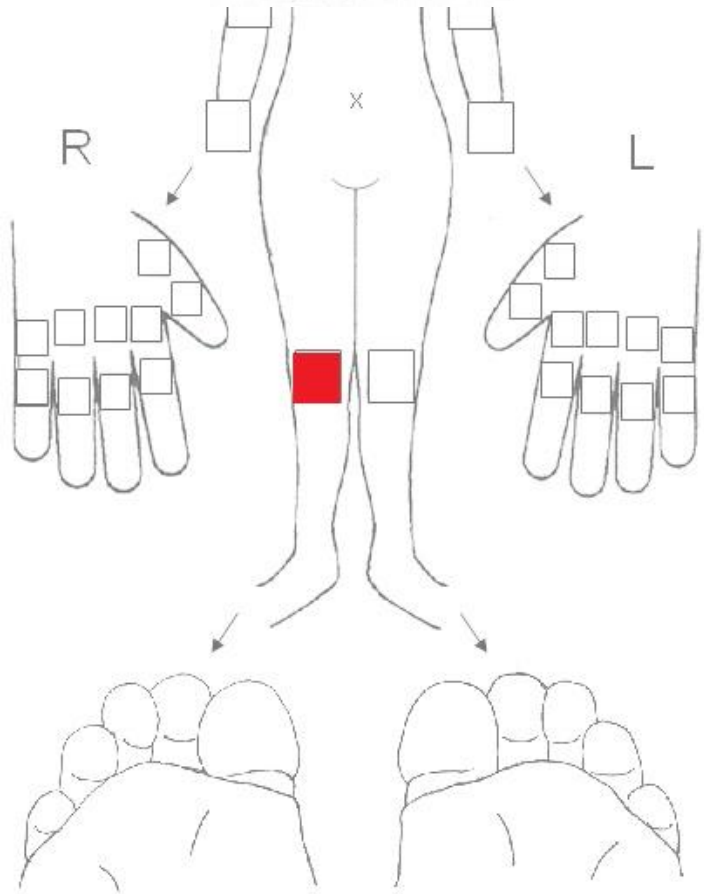
IN THE SECOND ACT THEY LIVE AS PEOPLE WITH A LONG-TERM CONDITION, AND THEY OFTEN GRIEVE THE FIRST ACT.

Personal Story





- KNEE BIOPSY IN 1977: JIA
- PHYSIOTHERAPY
- JOINT ASPIRATION
- NSAID
- INTRA-ARTICULAR INJECTIONS (AGE 8 TO 10)
- 1st REMISSION (~15)





- AGE 22 SUDDEN SWOLLEN KNEE AND LEG AFTER REST

- KNEE BIOPSY (STILL JIA/RA); XRAY + CT SCAN

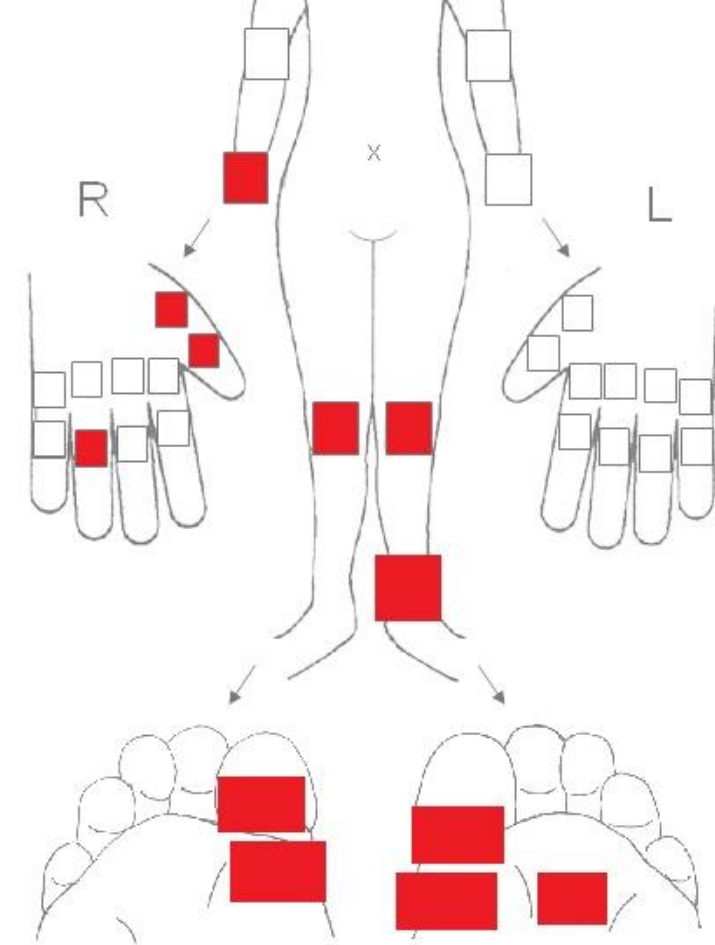
- ARTHROSCOPIC SURGERY (BOTH KNEES)

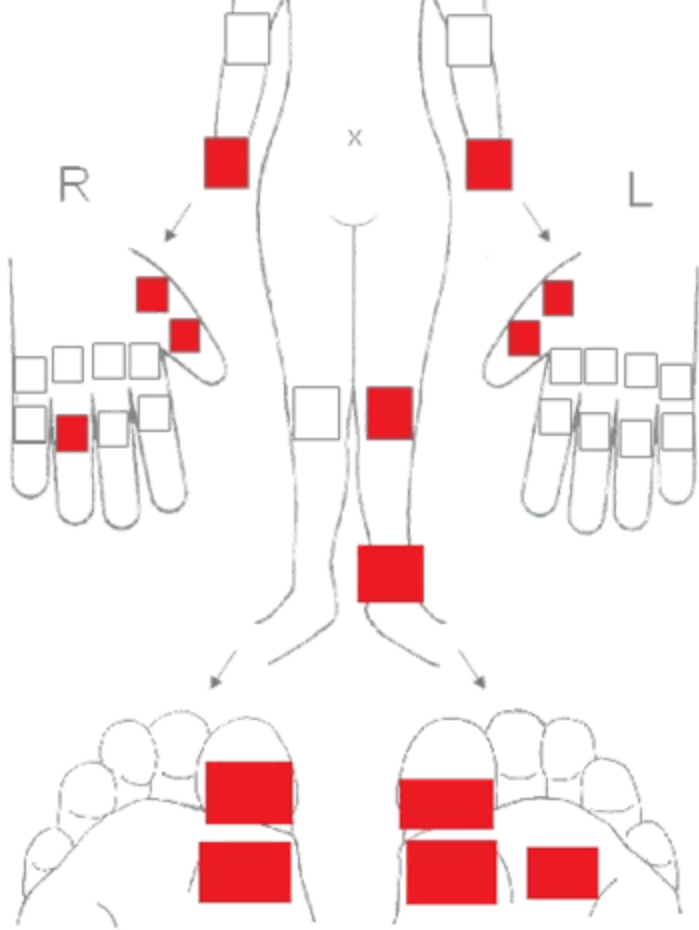
- INTRA-ARTICULAR INJECTION

- NSAID + SULFONAMIDE (1 YEAR) + GLUCOCORTICOID

- COX-2 INHIBITOR + GLUCOCORTICOID

- COX-2 INHIBITOR + GLUCOCORTICOID + IMMUNOSUPPRESSANT (INJ.)





- 1999 TOTAL KNEE REPLACEMENT
- NSAID + GLUCOCORTICOID
- PHYSIOTHERAPY + HYDROTHERAPY
- SUSPENDED IMMUNOSUPPRESSANT (TRYING TO GET PREGNANT)
- NSAID + GLUCOCORTICOID
- DECISION TO PROCEED WITH RA TREATMENT
- NSAID + GLUCOCORTICOID + IMMUNOSUPPRESSANT
- 2004 STARTED ANTI-TNF
- 2005-2006 LEFT WRIST + THUMB + MTP ARTHRODESIS
- 2017 & 2019 THUMB IP ARTHRODESIS
- 2023 JAKi



Collective experience

Experiential expertise

THEY CAN PROVIDE THEIR OWN INSIGHTS PLUS INSIGHTS THEY HAVE LEARNT FROM OTHERS IN THEIR PATIENT COMMUNITY.

THEY DO NOT NECESSARILY REPRESENT OTHERS' OPINIONS AND EXPERIENCES, BUT THEY CAN CONVEY WHAT THEY HAVE HEARD AND SEEN FROM THEIR PEERS, AND THEY ARE AWARE OF THE DIFFERENCES BETWEEN PATIENTS.

OVER THE YEARS, THEY LEARN TO UNDERSTAND THE RESEARCH CONTEXT AND PROCESSES.

Portuguese recommendations for the use of biological therapies in patients with rheumatoid arthritis – 2016 update

Duarte C, Sousa-Neves J*, Águeda A*, Ribeiro P*, Daniel A*, Eugénio G*, Serra S*, Araújo F⁶, Barcelos A³, Filipe B, Bernardes M⁸, Canhão H⁹, Cerqueira M¹⁰, Capela S⁴, Cordeiro A¹¹, Costa F¹², Costa L⁸, Cruz M¹³, Cunha-Miranda L¹⁴, Duarte C¹⁵, Falcão S⁴, Faria D², Figueira R¹⁵, Freitas JP¹, Gonçalves MJ⁴, Madruga Dias J¹⁶, Melo Gomes J¹⁷, Mourão AF¹⁸, Neto A⁷, Oliveira Ramos F⁴, Pimenta S⁸, Pinto P¹⁷, Polido-Pereira J⁴, Ponte C⁴, Ramos J¹⁹, Rodrigues A⁸, Santos H¹⁴, Santos MJ¹⁰, Sepriano A³, Silva C¹⁴, Tavares Costa J¹⁹, Teixeira F¹⁹, Teixeira V⁴, Valente P²⁰, Vieira-Sousa E⁴, Barros R⁴, Abreu P²¹, Fonseca JE

ACTA REUMATOL PORT. 2017;42:112-126

TABLE I. INSTRUMENTS TO MEASURE RHEUMATOID ARTHRITIS DISEASE ACTIVITY AND TO DEFINE REMISSION (ADAPTED FROM 6)

Instrument	Thresholds of disease activity	
DAS28-ESR ²⁵	Remission	<2.6
	Low Activity	≥2.6 to <3.2
	Moderate Activity	≥3.2 to ≤5.1
	High Activity	>5.1
SDAI ²⁶	Remission	≤3.3
	Low Activity	>3.3 to ≤11
	Moderate Activity	>11 to ≤26
	High Activity	>26
CDAI ²⁷	Remission	≤2.8
	Low Activity	>2.8 to ≤10
	Moderate Activity	>10 to ≤22
	High Activity	>22

DAS 28-ESR: 28-joint Disease Activity Score Erythrocyte Sedimentation Rate; SDAI: Simplified Disease Activity Index; CDAI: Clinical Disease Activity Index

DAS28CRP 3.63
activity Moderate

DAS28CRP disease activity
>4.1 high
2.7~4.1 moderate
<2.7 low
<2.3 remission

Stanford HAQ 20-Item Disability Scale

Please check (✓) the one best answer for your abilities over the past week.

At this moment, are you able to:	Without ANY difficulty	With SOME difficulty	With MUCH difficulty	UNABLE to do
DRESSING & GROOMING				
1. Dress yourself, including shoelaces and buttons?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Shampoo your hair?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ARISING				
3. Stand up from an armless straight chair?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Get in and out of bed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
EATING				
5. Cut your meat?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Lift a full cup or glass to your mouth?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Open a new milk carton?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
WALKING				
8. Walk outdoors on flat ground?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Climb up five steps?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please check any AIDS OR DEVICES that you usually use for any of the above activities:

- Devices used for dressing (button hook, zipper pull, etc.)
 Special or built up chair
 Built up or special utensils
 Cane
 Walker
 Crutches
 Wheelchair

Please check any categories for which you usually need HELP FROM ANOTHER PERSON:

- Dressing and grooming
 Eating
 Arising
 Walking

Source: https://www.eular.org/tools_products_.cfm



YOU KNOW YOU HAVE RHEUMATOID ARTHRITIS WHEN...

RA GUY
Giggles Over Tears with RA



... by the time you've finally reached a standing position, you forget why you were even moving in the first place..
- RA Guy

YOU KNOW YOU HAVE RHEUMATOID ARTHRITIS WHEN...

RA GUY
Giggles Over Tears with RA



...you change your hairstyle to "tousled" and pretend it was a style choice.
- Halo

- BEING ME. BEING ABLE TO BUY CLOTHES AND NOT HAVING TO THINK ABOUT BUTTONS. BEING ABLE TO WEAR ANY TYPE OF SHOES. BUT MAINLY BEING PAIN FREE AND BEING ABLE TO PLAY WITH MY GRANDDAUGHTER.
- GOING ON A DATE AND NOT THINKING ABOUT THE AWKWARD MOMENT HE REALIZES I HAVE TO USE CRUTCHES TO GET AROUND.
- FEELING LIKE ME AGAIN. ENJOYING THE SPORTS I LOVE AGAIN, SOCIALIZING LIKE ME AGAIN, DRESSING LIKE ME AGAIN (NOT HAVING TO HIDE SWOLLEN KNEES AND ANKLES).



REMISSION
MISSION

What does Remission mean to you?


From something as simple as being able to brush your teeth, do the gardening or work full time, the word remission truly means different things to each of the 690,000 people in the UK living with rheumatoid arthritis (RA), as well as their family and friends who see them coping with the disease daily.

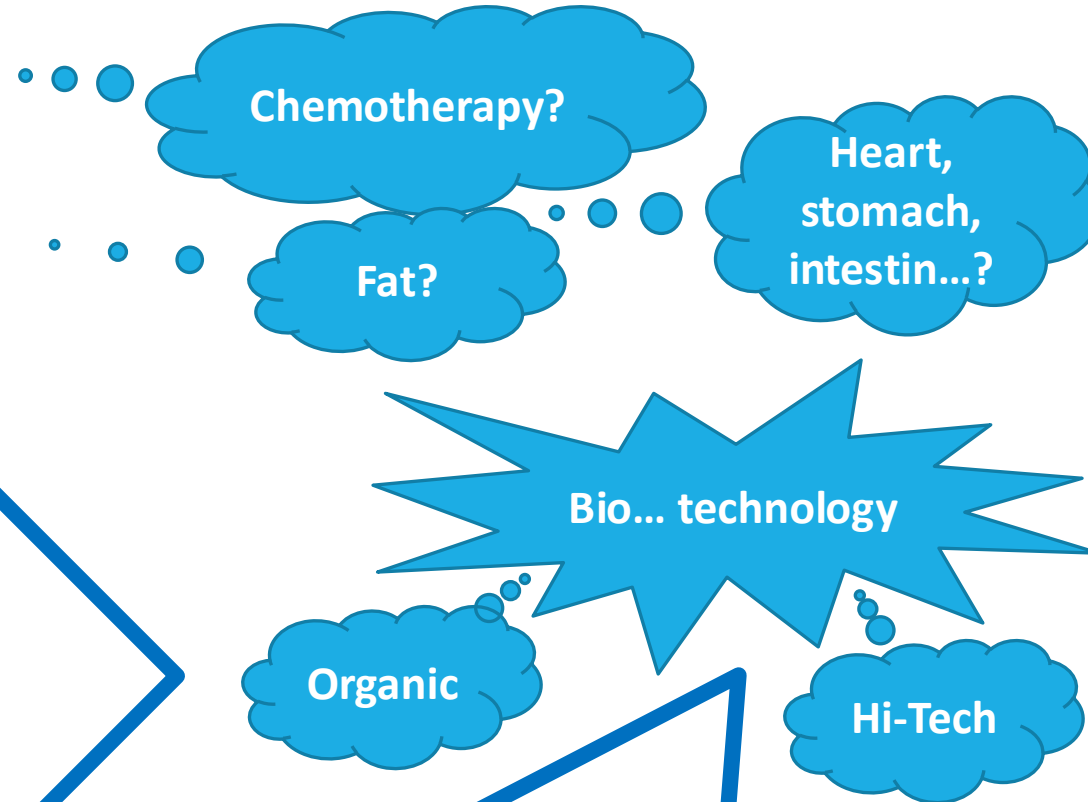
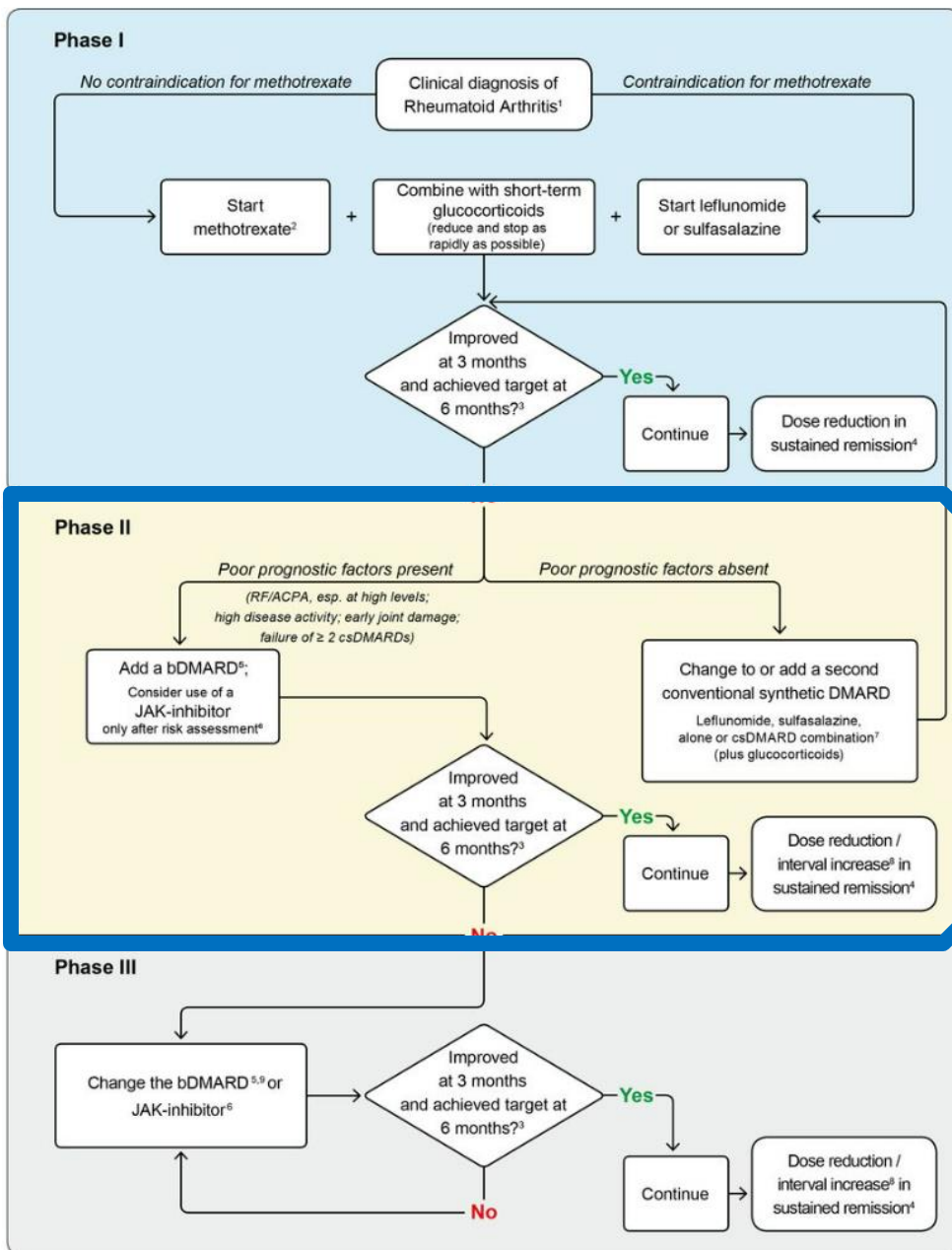
It's really easy to join our Remission Mission - simply take a photograph of yourself, upload it to the photo wall and tell us what remission means to you! The photo wall is open to everyone with RA, family members and friends, regardless of age.

Share your mission with #RemissionMission

Join the mission 

Watch all the videos 

Find out more about DAS 



- a) You have to be in a worst condition to have access;
- b) You have to had tryied several treatments before (gone through successive failures)

- INNOVATION

-  PHASE IV STUDIES AND REAL WORLD EVIDENCE
 -  HEALTH LITERACY

- EQUITABLE ACCESS

-  AWARENESS, AVAILABLE RESOURCES, PATIENTS' VALUES

- SUSTAINABILITY / AFFORDABILITY

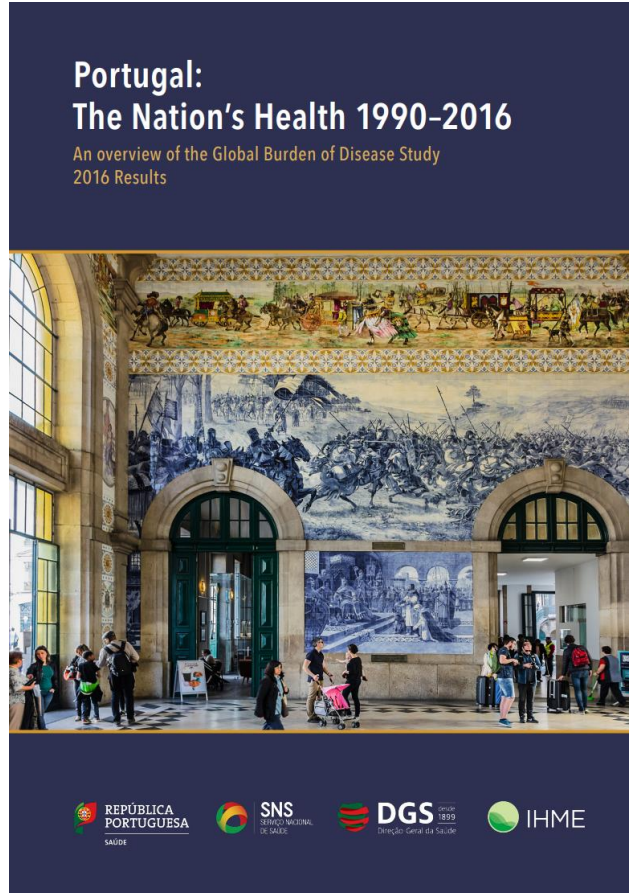
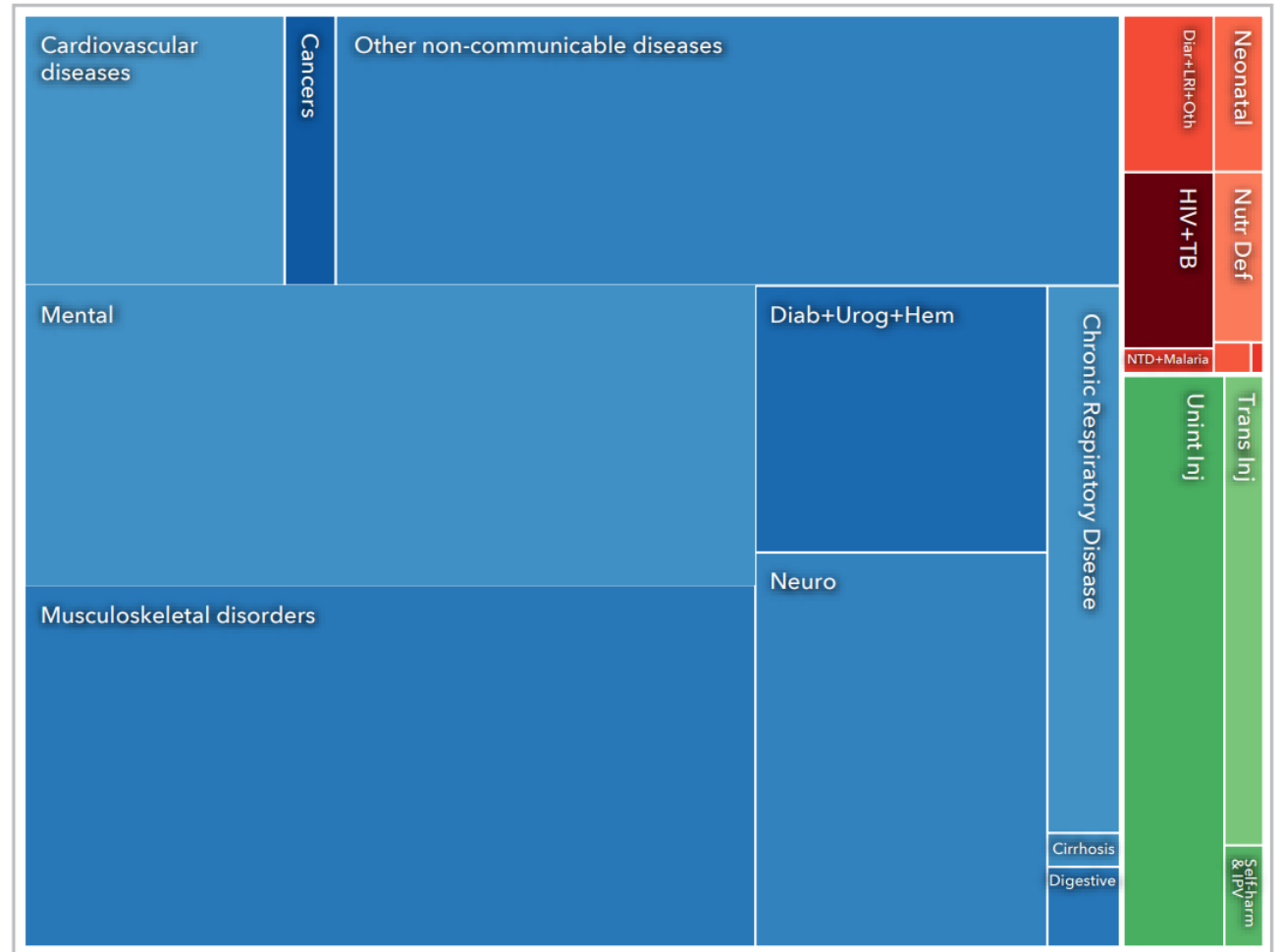
-  INCLUDE INDIRECT COSTS / ABILITY TO WORK ?
 -  COMPETITIVITY (GENERICS, BIOSIMILARES)

References (previous slide image):

Smolen JS, Landewé RBM, Bergstra SA, et al EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs: 2022 update *Annals of the Rheumatic Diseases* 2023;82:3-18.

Distribution of total YLDs by cause of disability (%), both sexes, Portugal, 2016

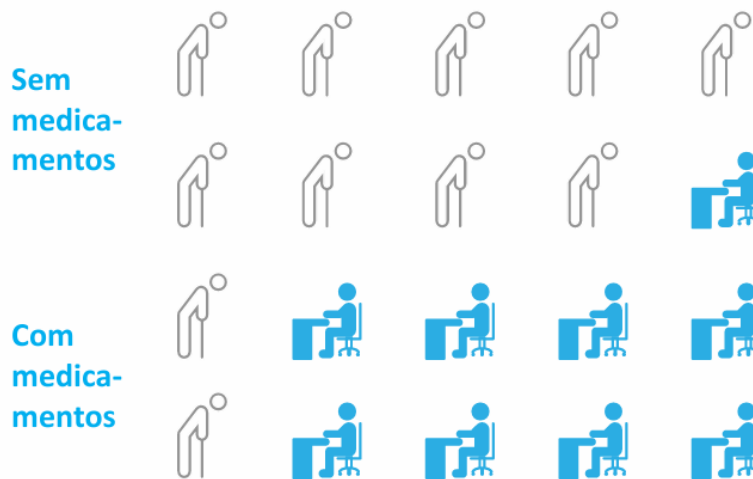
- Communicable, maternal, neonatal, and nutritional diseases
- Non-communicable diseases
- Injuries





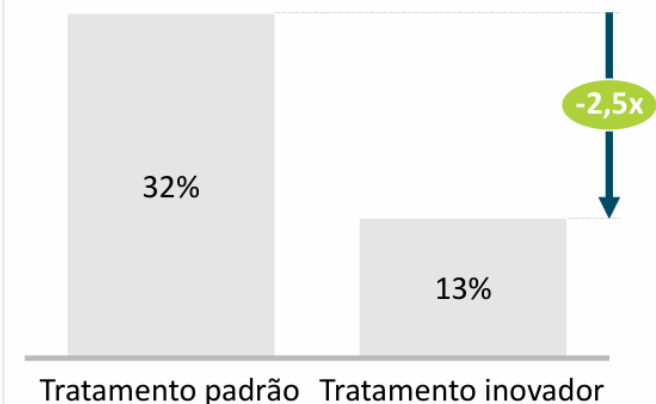
B Medicamentos inovadores permitiram aos doentes com Artrite Reumatóide continuar a trabalhar e evitar a reforma antecipada

Artrite Reumatóide – medicamentos permitem a 18 mil doentes gerar 240 M€ em salários, sustentando-se e às suas famílias



- **Medicamentos permitem a doentes com AR evitar a reforma antecipada** e a manterem-se activos, em vez de terem de se reformar cerca de 3 anos após o surgimento da doença
- **Estima-se que os doentes com AR que continuam a trabalhar são ~1 em 10 sem medicamentos e ~8 em 10 com medicamentos**
- **O impacto dos medicamentos é de 240 M€**, equivalente a 18 mil doentes a ganhar ~13 mil €/ano cada

Artrite Reumatóide – medicamentos mais recentes permitem aos doentes ter ~2,5x maior probabilidade de continuar a trabalhar após 2 anos



- **Os doentes que recebem biológicos têm 2,5x menos probabilidade de se reformar** e são capazes de trabalhar mais 31 semanas
- **~8 mil € em salários adicionais por doente** em Portugal associados a semanas adicionais no trabalho

Apifarma – perspectiva holística sobre o valor dos medicamentos em Portugal
Outubro de 2018

"We combined all your medications
into ONE convenient dose."



Be patient with me...
Everyone is
on the same roller coaster
we all just have
different seats!

~ Original C.Jay Quote ~

