Understanding and improving communications between people with rheumatoid arthritis and their healthcare professionals

What does remission mean to you?

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Foreword

Remission is the hoped for ultimate clinical goal for most people with rheumatoid arthritis (RA).

However, education and awareness are essential, because even if people with RA are not experiencing disease symptoms, long-term joint damage can still occur and this can, in some cases, lead to disability and the need for joint replacement surgery.\(^1\)\(^2\)

The ‘What does remission mean to you?’ campaign was designed to highlight and increase understanding of what remission means to people with RA and improve communication between them and healthcare professionals (HCPs), to encourage better outcomes for people living with the disease.

RA affects an estimated 690,000 people in the UK. There are approximately 26,000 new diagnoses each year; with occurrence of RA 2-4 times more likely in women than in men. The onset of RA most commonly occurs between the ages of 40-60 years, however all cases are individual and it can affect people of any age.\(^3\)
RA is a painful and debilitating auto-immune disease causing swelling and damage to cartilage and bone around the joints. It is a chronic condition currently without a cure and this can have a huge impact on the psychological health of a person with RA, their friends and their family. However, with the appropriate treatment, RA can be a manageable condition.

There are many ways to manage RA with treatment options such as disease modifying anti-rheumatic drugs (DMARDs) and biological therapies. Every patient should have their Disease Activity Score (DAS28) reviewed at each consultation with their HCP, because regular clinical assessments are very important to ensure disease progression is monitored and treatment options continue to remain appropriate. If RA is managed effectively, people with RA should be able to lead fulfilling lives, reducing the long-term damage to joints and helping to achieve the lowest disease state possible for them.

Understanding and defining what remission means to an individual and for patients’ own personal goals to be acknowledged and taken into account by health professionals are important when managing the disease, to ensure best treatment, outcomes and experience for every patient.

Ailsa Bosworth
Chief Executive
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Executive summary

The ‘What does remission mean to you?’ survey, conducted amongst members of the National Rheumatoid Arthritis Society (NRAS), saw a fantastic response rate: 1,100 people with RA took part. The survey aimed to uncover insights into the views and experiences of people living with RA, unearth the understanding of the term ‘remission’ and what remission means to them. This report presents the results of the survey and aims to highlight the importance of communication between HCPs and people with RA, the form this might take and the consequences of HCP/patient interaction.

Key findings from survey

- Remission in RA is generally poorly understood by people with the disease
- Over 80% of people with RA do not know their DAS28 score and over 75% never set personal treatment or DAS28 related goals
- 93% of people with RA do not know the definition of a clinical DAS28 remission score and 89% have never had a DAS28 goal set by their HCPs
- There is a mismatch between how HCPs define remission and what people with RA understand by the term
- People with RA set and work towards personal goals instinctively, yet the setting of and aims of clinical goals are largely overlooked by people with RA
- 86% of people with RA believe more education about RA is needed for people with RA
- 65% of people with RA believe more education is needed for HCPs
- RA specialists are not seen to be proactive in driving people with RA towards either considering or achieving remission
Methodology

The ‘What does remission mean to you?’ survey comprised 34 questions. The content and tone of these questions were developed following a focus group in August 2012 with 11 NRAS members who were asked to discuss what remission meant to them.

Upon confirmation of the questions, the survey was shared with the same participants from the focus group to ensure all issues and concerns were captured accurately.

Once the questions were confirmed, the survey was uploaded to Survey Monkey – an online survey and questionnaire tool – and a link was despatched to NRAS members via email. The link to the questionnaire was also included on the NRAS website and their social media sites (Facebook and Twitter). This allowed NRAS members, as well as non-members, to complete the survey.

The questionnaire was made available online in December 2012 and in just two months the survey received an impressive 1,100 responses.
Understanding remission
Achieving remission has been referred to as the ultimate goal of RA treatment. With any ambition, a clearly defined endpoint to aim for is imperative. This is particularly pertinent when considering incurable conditions such as RA, given the psychological implications the chronic condition can cause.

Worryingly, the 'What does remission mean to you?' survey revealed that:

- Only 31% of people with RA feel their disease is well controlled.

- People with RA are not necessarily aware of the diversity of the treatment options available to them.

- Only 13% of people with RA understand remission in terms of achieving a DAS28 score of less than 2.6, with 50% and 48% understanding remission to be 'symptom free' and 'pain free' respectively.

- 52% of people with RA never talk to their HCP about remission. 64% do not know how HCPs define remission.

- Empowerment of people with RA relies on them being actively engaged with HCPs, strengthened by end goal targets. There is a strong opportunity for more effective communication between people with RA and HCPs.
What do you think are the barriers to you achieving remission?

- Late diagnosis
- Long term disease/joint damage
- Not seeing HCPs frequently enough
- Own treatment adherence
- Treatment not being effective for me
- Treatment side effects

Number of respondents
What do you understand by the word ‘remission’ in RA?
The Disease Activity Score (DAS28) is a combined index that measures disease activity and monitors disease progression in people with RA. It combines information from 28 tender and swollen joints (not including feet or ankles), erythrocyte sedimentation rate, and a general health assessment on a visual analogue scale. The clinical definition of remission is a DAS28 score of less than 2.6.¹⁰

Aiming for remission in RA is important for many reasons. From a clinical perspective, reaching remission means a person with RA will not suffer unnecessary disease progression, protecting them from joint destruction, pain and limitations in mobility. From a personal perspective, aiming for remission ensures a person with RA is fully aware of how their condition is changing, is motivated to reach their goals and understands how this can positively impact their day-to-day lives.

However, currently there is a substantial need to increase awareness and education around remission as the survey results show:²⁸

- 82% of people with RA do not know their DAS28 score, 80% measure treatment goals through reduction in medication.
- 93% of people with RA do not know the DAS28 score required to reach clinical remission. 89% have never had DAS28 goals set and 55% do not know if achieving a DAS28 score of 2.6 is ‘realistic’.

DAS28 offers a comprehensive, empirical measurement of disease activity and progression to remission. There is distinct shortfall in communication around DAS28 and clinical goal-orientated treatment plans.

To find out more about DAS28, visit the ‘Know your DAS’ section of NRAS’ website at: www.nras.org.uk/about_rheumatoid_arthritis/established_disease/disease_activity_score_das/patient_materials.aspx
Do you know your DAS28 score?

- Yes: 18%
- No: 82%

Do you know what DAS28 score you need to attain in order to reach ‘clinical’ remission?

- Yes: 7%
- No: 93%
Goal-orientated treatment plans: the pathway to remission

Setting goals for treatment in RA is very important. It provides focus and motivation for a person with the disease to understand what can be achieved in terms of their own disease state. Goals also allow for progress to be measured; whether that is the progress made towards reaching clinical remission, or how a person is progressing with specific treatments.

Most importantly, open channels of communication and goal-setting ensures HCPs and their patients work towards a common purpose and this in turn achieves the best possible outcome for the individual. The survey found:

- 93% of people with RA think it is important or very important to achieve personal goals but only 50% feel it matters to their HCP whether they achieve their personal goals.
- Only 11% of respondents believe that people with long standing RA are most likely to achieve remission. 56% believe the main barrier to achieving remission is long-term disease/joint damage.
- Many people with RA measure success of their treatment by personal goals and not just clinical results.
- People with RA do not feel confident in aiming for or achieving remission.

93%  11%
The effects of RA: what would you like to do that you can’t currently?
Education: the road to empowerment

It is not only organisations such as NRAS that see the need for education to bridge the gap in knowledge of the disease and of remission in people with RA. It is also the people with RA themselves that recognise more education is required and essential to improving outcomes for people with RA:

86% of respondents believe more education/awareness is needed for people with RA around remission and 65% feel more education/awareness is needed for HCPs around remission.

90% of respondents think that more education/awareness is needed for people with RA around the irreversible damage caused by RA and the impact this may have in the long-term.

This highlights key concerns for people with RA and a need for more awareness around the term remission and what it means on a practical level.

NRAS is committed to providing support and information for people with RA, their families, friends and carers. To find out more visit www.nras.org.uk, Freephone 0800 298 7650 or email helpline@nras.org.uk
Do you think that more education/awareness is needed around remission in RA?

![Bar chart showing responses to the question for patients and healthcare professionals (HCPs). The chart indicates a significant number of respondents (over 800) for patients who believe more education/awareness is needed, while the number is much lower for HCPs.](chart.png)
Calls to action from NRAS

These survey findings show the need for better HCP-patient interaction in order to attain improved treatment outcomes, day-to-day experiences and disease states of people with RA.

Summary of key survey findings:
• People with RA are not necessarily aware of the diversity of the treatment options available to them
• There is a distinct shortfall in communication around DAS28 and clinical goal-orientated treatment plans
• Empowerment of people with RA relies on them being actively engaged with HCPs, strengthened by personal and clinical end-goal targets
• There is a strong opportunity for more effective communication between people with RA and HCPs when considering long-term effects of RA, treatment goals and what remission means for individuals
• People with RA do not feel confident in achieving or aiming for clinical remission

Our calls to action:
• Improve education/awareness of clinical remission in RA and of DAS28 for people with RA and HCPs
• Highlight the importance of DAS28 as a tool to regularly monitor disease progression in order to review treatment and encourage progression towards clinical remission for as many people with RA as possible
• Improve communication between HCPs and people with RA about achievement of personal and clinical goals, as well as clinical remission
References


7. NHS Choices, Rheumatoid Arthritis - Treatment http://www.nhs.uk/Conditions/Rheumatoid-arthritis/Pages/Treatment.aspx [last accessed September 2013]

8. Data on file: Survey results


NRAS Publications

Other publications that you may find useful with regard to other aspects of your RA are shown below and are available from NRAS.
The ‘What does remission mean to you?’ survey is a collaborative project between the National Rheumatoid Arthritis Society, Roche Products Ltd and Chugai Pharma UK Ltd. This project is funded by Roche Products Ltd. and Chugai Pharma UK Ltd.