
Spotlight on RA: PERSPECTIVES ON LIVING WITH AND TREATING RHEUMATOID ARTHRITIS



Eli Lilly and Company Ltd and NRAS collaborated to produce this report.
Eli Lilly and Company Ltd sponsored and contributed to the design of this report.

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FOREWORD



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Since the turn of the century, we have seen the treatment of rheumatoid arthritis (RA) change in a revolutionary way. I was diagnosed over 35 years ago when the delivery of care was very different to the treatment pathways we know today. This led to me sustaining a huge amount of irreversible damage and a level of disability which would be unlikely to occur, were I diagnosed today. In fact every year, since the launch of NRAS in 2001, we have seen major growth in the research of the pathogenesis of RA, spawned by the advent of Anti-TNF inhibitors in the late 90s. There has justifiably been much emphasis on the need for early diagnosis within 12 weeks of symptom onset, Treat To Target and tight control strategies, all of which we champion at NRAS. However, in spite of this remarkable progress, we still face many challenges and wide variation in care, as revealed by the NRAS survey done in collaboration with Eli Lilly and Company Ltd and conducted by ComRes, which you can find in the centre of this report.

The survey revealed that 48% of people who participated reported waiting more than three months after their initial visit to the GP before they saw a rheumatologist which does not meet the NICE Quality Standard recommendation of referral within 3 working days of presentation of symptoms.¹ Also, worryingly over a quarter (26%) waited more than year before getting

a formal diagnosis.¹ Some of these statistics broadly align with other recent reports, such as the HQIP national audit on early inflammatory arthritis/rheumatoid arthritis.

Many people feel that their disease is 'hidden'. Again this is a common theme amongst people with RA as the two major symptoms, pain and fatigue, are invisible and it can be very hurtful when others minimise your disease or dismiss it as 'not very serious' because they don't understand what it is. The essays in this report reflect some of these issues in a very eloquent and sometimes poignant way and I would urge you to read them.

So, the challenges are clear: we need to speed up the process of diagnosis and reduce the three major areas of delay which currently exist, through addressing the lack of public awareness of the early symptoms of RA, GP education and awareness of need to refer rapidly, and, the ability of specialist care to see referred patients within three weeks. Delivering best care actually costs the NHS less than delivering sub-optimal care and it's not always about money. Strong local clinical leadership and willingness to change the way in which resources are used can make a positive difference, such as introducing an early inflammatory arthritis clinic. Also sign-posting

RECOMMENDATIONS

We want to speed up the process of diagnosis and reduce three major areas of delay:

- **Addressing the lack of public awareness of the early symptoms of RA.**
- **Supporting GP education and boosting awareness of the need to refer rapidly.**
- **Ensuring patients can receive timely specialist care.**

Delivering best care can actually cost the NHS less than delivering sub-optimal care and getting the best outcome which is right for the individual is the most important goal.

Strong local clinical leadership and a determination to change the way in which resources are used can make a major positive difference, such as introducing an early inflammatory arthritis clinic.

Patients should be sign-posted to organisations such as NRAS who can offer them a tailored support package to help them manage and live with their condition as effectively as possible.

There needs to be real shared decision making between clinicians and patients about their care enabling patients to set goals that matter to them.

patients to organisations who can help, like NRAS, can make a life-changing difference, yet in the ComRes survey only 30% of participants received advice on where to find additional information and support.¹

Involving patients in real shared decision making and care is another area which was highlighted as an issue for patients – in other words it's not happening widely enough! This requires behaviour change in both health professionals and patients and is an area we are actively addressing as an organisation. Historically, patient centred care has been talked about a great deal by successive governments but little has been done in real terms to invest in it or prioritise its implementation. We are therefore delighted to see that the Government is now addressing this more constructively in the new NHS England business plan and is putting in place plans to introduce a self-



care programme for people with long term conditions, which we whole-heartedly support.

I'd like to extend my thanks to our collaborators on this important report and hope you will find the essays revealing and informative.

1. ComRes. Data on file. Survey of patient experiences of rheumatoid arthritis. December 2015.

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THE COURAGE TO SAY WHAT YOU WANT



KATY PIERIS

Katy has lived with rheumatoid arthritis for the last five years. Here, she reflects on her experience of care and how we can ensure excellent care for people with RA.

Rheumatoid arthritis can be a frightening disease when it is first diagnosed. When I was first diagnosed five years ago, I struggled to get involved in my care. At the beginning, they give you a bunch of leaflets, largely provided by health charities, which are very focused on the medications which are available. I, along with many other patients like me, had to go out and do a lot of research myself on my condition in order to feel informed. I think, off the top, patients need more information to educate themselves, especially on how to manage the condition's effect on their lifestyle. That is the start of getting patients involved in the process of confronting RA.

There are a number of different barriers to patients like me being involved in the big decisions about their care. The first is that the quality of consultants can vary considerably. I hear from talking to a lot of fellow patients whom I have met that there are good and bad consultants out there. I have been lucky with my current consultant, but I am changing to a new consultant, so I will wait to see what the outcome will be. And that uncertainty does make me a little nervous about what my care will be in the future.

Some consultants are very set in their ways about how to treat RA and are reluctant to change their prescriptions to suit what a patient feels they need. That creates a crucial obstacle to people with RA being more constructively involved in big decisions.

Patients also experience a "postcode lottery" when it comes to the quality of care they receive in hospital.



“ One can get the impression that hospital care is about ticking boxes, and about procedure instead of outcomes ”

Since RA requires considerable specialist care, patients rely on hospitals to manage their condition. Some hospitals, as I understand it, are more forthcoming in funding biologics treatments than others. All of a sudden, budget pressures on the news and in the papers become very real. That makes people with RA conscious of the money, which also distorts the choices they make about their own care. I do not think anybody would argue that patients should be influenced by budgets when deciding what they want from their treatment.

As a patient, I have always wanted to be able to focus on managing my condition, however hospitals can pose another barrier. One can get the impression that hospital care is about ticking boxes, and about procedure instead of outcomes. That approach makes the health system revolve around what doctors are doing rather than how their patients are doing.

I think we can overcome these barriers if we renew our focus on the patient, perhaps more than on the disease. I for one would have liked to understand better from diagnosis not only the treatment options available but also the effect on my lifestyle. Advice that focuses on the medication being prescribed is helpful, but it does not necessarily prepare you for managing the effects of joint pain, fatigue, and every other side effect on how to go about your daily life.

Healthcare professionals (HCP) could do more to empower patients to say what they want, and to work on setting goals with their patients, based on what patients want to achieve. For a lot of people with RA, this will mean setting smaller, "mini-goals" with their HCP, based on their ability to do a certain activity, like going to the bathroom or going for a walk.

For this to work, patients also need to have the courage to say what they want rather than relying on professionals to give advice. This can be intimidating, but everyone with RA has to remember that the point of their treatment is to make them feel better and lead a fully and happy life, and nothing else.

I do understand that clinicians might not always feel comfortable relying on patient input. They might not want to have needy patients impacting too much on their budget – but we need to have the dialogue between HCPs and people with RA if we want to treat the whole person. Now, for instance, people are not routinely offered mental health care by their specialists – this should be a

“ Most people with RA feel they have a 'hidden condition' ”

part of the standard care packages. The effects RA can have on patients' emotional well-being, from their friendships to relationships and work, are well documented so we need to meet the challenge head-on.

Giving patients the full package of care means getting stakeholders beyond the healthcare providers involved. Independent charities and patient organisations have a massive role to play in this. They can focus on what's best for you as a person – sometimes they are more helpful than the actual hospitals. They often have more flexibility than healthcare professionals to focus on the person rather than on procedures and targets. In that sense, they are an essential complement to the medical expertise provided by nurses, GPs, and rheumatologists.

The charities also let patients know they are not alone. Through events at NRAS and other bodies, I have met countless other people living with RA. We can swap stories, exchange tips, give advice, and just talk. The ComRes survey which NRAS and Lilly have just published showed that most people with RA feel they have a "hidden condition"¹. The charities remind us that there are other people out there to give us support, so we don't need to suffer in silence.

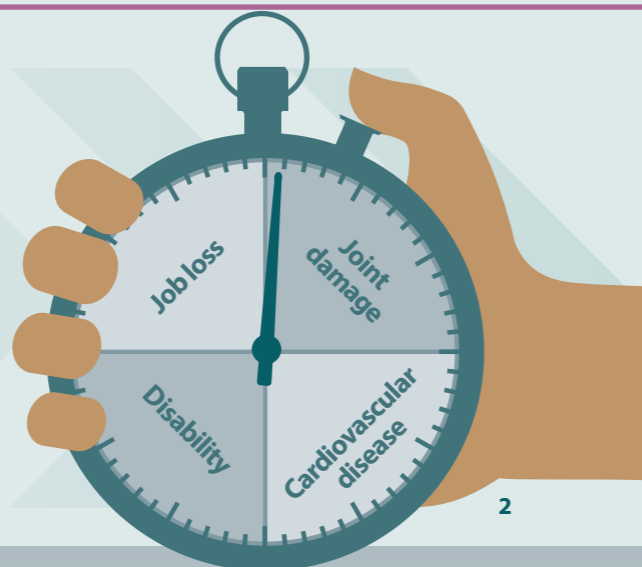
RA takes a lot to manage – from lifestyle, to mental health, and various courses of treatment. But if we focus on giving patients the tools to be involved in setting their own goals alongside their HCPs and their families, and if we make care about the patient, not the process, all of us with RA can lead full and happy lives.

CHALLENGES AT EVERY STEP: CURRENT MANAGEMENT OF RHEUMATOID ARTHRITIS

Early diagnosis is key

for people living with RA.

NICE says there are **potentially devastating effects to late diagnosis.**¹



NICE guidelines

recommend any patient who seeks medical help after more than three months with symptoms should receive an

urgent specialist referral.³



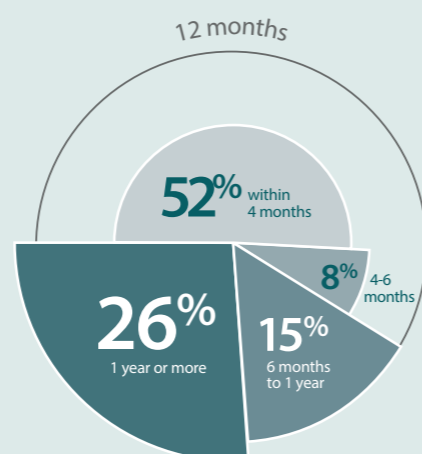
Only **35%**



of patients report being **referred immediately** by their GP to specialist care for **suspected RA.**

3% of survey respondents reported that their GP diagnosed RA immediately.⁴

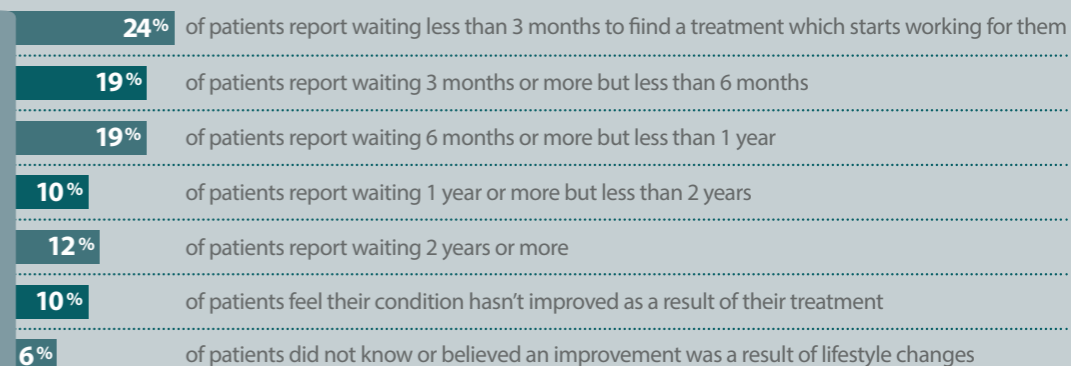
A **majority** of patients receive a diagnosis **within four months** of the onset of symptoms, but for some this can take longer.



Time from onset of symptoms to diagnosis⁴

Please note that due to weighting and rounding of the data, percentage figures for single choice questions may not always add up to 100%.

Even after diagnosis, many patients can wait a **further six months** to find a treatment which starts working for them.⁶



When patients do **receive a diagnosis**, only

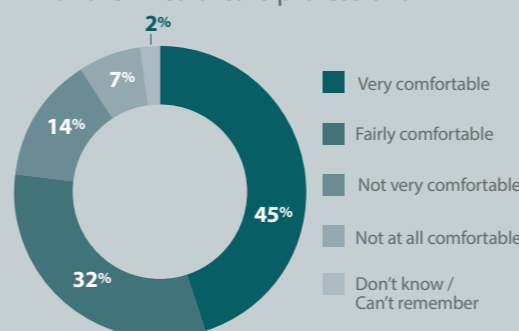
30%

reported receiving **advice from an HCP** on where to find additional information and support.⁴



Not all patients

feel comfortable discussing their diagnosis with their healthcare professional⁴



48%

of patients agree that their friends and family **don't understand** their condition enough to be able to offer adequate support.⁴



People with **rheumatoid arthritis** deserve **early diagnosis within 3 months, effective treatments, and support** to lead a **full and healthy life.**



References

1. NICE. Rheumatoid arthritis in over 16s: Quality Standard www.nice.org.uk/guidance/qs33 June 2013 (Accessed May 2016)
2. Ibid.
3. NICE. Rheumatoid Arthritis in Adults: Management www.nice.org.uk/guidance/cg79/chapter/recommendations December 2015 (Accessed May 2016)
4. ComRes. Data on file. Survey of patient experiences of rheumatoid arthritis. December 2015

"YOU'RE WORTH IT"



ERICKA WALLER

Ericka has lived with rheumatoid arthritis for four years. Perhaps better known to audiences as Mum In the South from her blog on life and living with RA, here she offers a personal reflection and some thoughts for other people with the condition.

Rheumatoid arthritis is not a condition for the faint-hearted cowardly lion. Coming to terms with RA is a process, a journey. RA is not just chronic pain. It means chronic fatigue, mental exhaustion, depression, anxiety, brain fog, and clumsiness. It means accepting your life will never be the same. It means making compromises and letting go of things that you once took for granted. Too often, it also means fighting against a system which still puts up too many obstacles for people who find themselves with RA.

From the beginning, many people find it difficult to receive a firm diagnosis. I was told I had fractures, diagnosed with gout, and left to suffer irreparable damage to my toes before I was even diagnosed with RA. For a start, GPs need to receive better training about the condition, and to be made aware of changes and developments in the field as they happen.

Patients also often do not have the confidence to challenge their healthcare professionals. You have to be quite proactive in standing up to GPs and specialists, which can be quite intimidating. I let myself get sent away with a flea in my ear too

“When it comes to RA, think like the hair care advert. “You’re worth it””

many times. It was not until the pain got so sore I could not bear the breeze on my skin that I found my voice and demanded a second opinion. If you do not push, you will struggle to get on to the best treatment.

RA is not a self-inflicted disease, and RA patients need to know that. So I say, when it comes to RA, think like the hair care advert. “You’re worth it”.

To make patients feel like they’re worth it, we need to start at the beginning with diagnosis. It shouldn’t be a battle to get an MRI, and scans should be done much faster. Blood tests too often do not show the overall severity of RA, and that means they stop people getting the treatments that work for them. Patients should also get an information pack when they are initially diagnosed with information about NRAS and other RA support sites and charities. It could also have a detailed synopsis of RA and what will happen next. That basic information should include information on mental health care too. No one talks to you about that side of things, but it can tip over into a real problem. Support for partners is critical here: my husband had to live in the shadow of my illness for a long time. He had a life, he had problems too, but I trumped him every time with my RA pain and my problems. It added pressure to our relationship. The resources for partners provide invaluable guidance on how to manage the strain, because the person at your side will mean so much to your care.

Another thing RA sufferers need to be informed about is the risk of having a compromised immune

system. I spend my life bouncing from one infection to the other. My local hospital is my second home. I want everybody else with RA to know how RA drugs can complicate infections and illnesses and how they should deal with that. Patients need to know they are not alone in confronting RA. I’d love to see RA support groups in doctor’s surgeries. They could host regular Q&A sessions with the RA nurse, and doctors could take the time to sit in when they could manage.

“RA is a massively misunderstood illness”

Once you’ve jumped through all the hoops needed to get diagnosed, referred to the right department, set up with an RA nurse, treatment programme and regular appointments with an RA specialist, you can have a good say in your care. But you need to get to know your support team. They will see you through the up and downs of RA, and they will know how you respond to treatment. You need to be able to talk to these people, because they are your friends in a system that is still too full with obstacles.

Charities can also play a huge role in helping support people with RA. There is a wealth of information online, once you are ready to tap into it, which can take time. This involves educating yourself, and your family about your illness. It took me a long time to get online: there seemed too much to take in. I started out just using the helpline, and it saved me. I had a real person at the end of the NRAS helpline who really knew what I was going through. Now, I go to online sites to read about developments, or to vent to fellow sufferers. I’m lucky to know some people who have RA, but most of my ‘pain-pals’ are online. I found them using forums or #rheumatoidarthritis, #ra, or #autoimmunedisease on Instagram and Twitter. We can swap tips, post

news about a flare-up, or share good articles about living with RA.

‘10 things someone with RA doesn’t want to hear’ is possibly the best article of them all. RA is a massively misunderstood illness. Even now my friends don’t understand my fatigue. My family and I have to plan all our lives round my need to sleep in the day. It means booking a hotel even for a day out, so I can go to sleep. It means the kids missing out on doing stuff with me. It means me losing chunks of my day, my life, to my illness. But that also means that friends and doctors think I should give up exercising, so I don’t feel tired and sore. But you can’t stop moving. Exercise keeps joints mobile and keeps depression away – and that’s what RA care should be all about.

That is, I guess, what I want people to take away. People with RA might not seem ill, but it is a big struggle with fatigue, depression, and the side effects of powerful drugs. But we can do so well if we get the right support from a speedy diagnosis through to a strong support network. In the end, we want people with RA running, playing, spending time with their kids, not behaving like a patient. If we tear down these barriers, we can lead happy and healthy lives.



NO 'ONE SIZE FITS ALL' APPROACH TO THE HOLISTIC CARE OF PEOPLE WITH RA



PROFESSOR PETER TAYLOR

Peter is the Director of Clinical Sciences and the Biomedical Research Unit inflammation theme at the Botnar Research Centre and leads the rheumatology clinical trials group and related translational research programme at the Kennedy Institute of Rheumatology within the Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences. He describes how treatment of RA has changed over recent years.

I am pleased to say that over the course of my career in rheumatology, there has been a dramatic improvement in the outlook for people newly presenting with RA. There are many reasons for this. We have learnt the importance of early treatment intervention, as well as how to most effectively use the drugs that have been available for a long time. Also important was the development of new classes of injectable drugs, as well as orally administered drugs, which have the power to effectively control inflammation and significantly limit or prevent joint damage. But not all patients respond to a given treatment option.

When recommending treatment for a patient with RA, one of my tasks as a rheumatologist is to assess which of the wide range of available therapies is most suitable for the individual person. A number of considerations will inform management decisions in which the patient is invited to be proactively involved. These include the efficacy and safety of the drug, tolerability, perceived convenience of the dosing regimen, the overall health of the patient and other medication that the patient might be taking.

Once drug treatment is initiated, therapy is generally administered according to response with the ambitious goal of attaining and sustaining a remission. This is the well-recognised Treat To Target (T2T) model.² With early treatment intervention, remission – defined as the absence of signs and symptoms of significant inflammatory disease activity – is achievable in a majority of patients, but by no means all. However, too few patients are seen as early as is desirable and of those who attain the target goal of remission, very few sustain it. And in the more established phases of

“With early treatment intervention, remission is achievable in a substantial proportion of patients”

RA, while remission remains the ideal treatment goal, maintained remission is aspirational for the majority. This then begs the question of how can we best treat those who do not achieve that target. A number of guideline recommendations for the treatment of RA have been produced from around the world. But given the heterogeneity of disease presentation and evolution, response to any given treatment and the widespread age range that can be affected, there is no 'one size fits all' approach to managing RA.

Where the T2T principles have been adopted, overall health outcomes are greatly improved for patient cohorts. But for those who do not attain the goal of remission, more personalised targets need to be formulated with a view to maximising quality of life. We need to set goals that are realistic for the individual, but can also help them achieve the best possible outcome. It is important to recognise that there is often a distinction between the physician-determined goal of a particular 'disease state' and a more functional goal relevant to the life of a person with RA. Examples might include cooking a meal, playing a round of golf, walking the dog or managing to go to work. The T2T approach sets remission as the desirable goal and where that is not achievable, low disease activity as a



secondary goal. The challenge, however, particularly in established RA, is that many patients are unable to attain to either goal and therefore the lowest disease activity state attainable by the individual can only be determined by many rounds of escalation of therapy or switching to alternative medicines. Therefore, both 'disease state' goals and personalised, functional goals are important. These are best realised when the physician takes time to understand each person's specific everyday difficulties and challenges and works with a multidisciplinary team to address them.

It is of note that the nature of unmet need in RA has changed over the last two generations, in part because of the very advances in treatment we have been discussing. As a consequence, it may not be at all obvious to a non-specialist that a person with RA has

“One of the key contemporary challenges in RA management is understanding and providing support for the 'hidden' effects of the condition”

the condition at all. They may look fit and well and the joints have a normal appearance. But a very different story may be revealed when the person with RA, who appears outwardly well, is asked how they feel. Fatigue, pain and depression are common problems for many people with RA who struggle to cope with the everyday demands of life while trying to keep up with their healthy peers. Therefore, for me, one of the key contemporary challenges in RA management is understanding and providing support for the 'hidden' effects of the condition. This can lead to a considerable effect on mood and emotions as people with RA struggle to balance the external perception of them against what they are really feeling. However, in part because of constraints of time in a busy clinic schedule, and in part because of an overemphasis on treating the disease state, rather than the patient who has the disease, physicians may not undertake an evaluation of a person's emotional wellbeing when they attend clinic.

In summary, the best outcomes for a person with RA can be achieved by optimising suppression of inflammation over time and having done this, identifying the key aspects of life of importance to the individual that continue to be impacted by RA. Earlier access to effective therapies is a key component to achieving the best possible outcomes and the prognosis for patients who present early is generally very good indeed. But all too often, people with RA are referred to specialists much later than is ideal. We must also work towards a system that offers the best possible care for people with RA who experience difficulties that fail to respond to a T2T management approach alone such as pain, fatigue and emotional difficulties. Health care providers looking after people with RA need to be equipped with the right tools and training to be able to talk to, assess and provide support for the emotional wellbeing of their patients. Patient groups and charities like NRAS are inspirational in providing practical and emotional support and encouragement for people living with RA, and we must encourage as much patient participation and engagement with these groups as possible.

GETTING THE RIGHT OUTCOMES FOR PATIENTS



DUANE MCLEAN

Duane McLean is Chief Pharmacist at a general hospital. He describes how medical professionals are working to meet patient needs and how new treatments are playing a role.

Pharmacists can sometimes come in for unfair criticism that their main interest is in saving money, but our key concern is patient safety and getting the right outcomes. Recent years have seen the conversation move on from clinicians saying what they want and commissioners telling them what they can afford. Even with NHS organisations facing financial pressures, the focus should not just be on reducing budgets. An increase in commissioning pathways now means there are more ways to optimise and manage treatments.

For example, in areas such as rheumatology, specialists and commissioners are now better able to talk about patient pathways and how appropriate use of treatment supports outcomes. While this is often a robust discussion, in many cases it becomes easier as more data on a treatment becomes available and part of a pharmacist's role is to help model the spending on medicines in order to support these clinical conversations. Better data and profiling of our patients has been a big improvement, leading to better medicines and managing appropriate use.

“ Better data and profiling of our patients has been a big improvement, leading to better medicines and managing appropriate use ”

This now enables us to explore the potential even for earlier and aggressive use of treatments, where in conditions such as rheumatoid arthritis this might reduce the risk of joint destruction and help keep people in work.

Access to treatment is often in the headlines, but at the local level there are also NHS organisations that are moving towards the mind-set of ensuring everyone who needs treatment has access to it, rather than unwarranted rationing. At the same time my job is to ensure the safe, clinical and cost-effective use of medicines – and with rheumatology coming second behind cancer in terms of spending, medicines optimisation to improve the prescribing, dispensing, administering or taking of medicines become even more important. This can range from working with home care providers to ensure medicines are delivered on time, which impacts patient experience, to helping provide education for patients on storing medicines properly.

New treatments and the way in which they are administered will also influence what we are saying to patients to boost adherence, including on how they use medicines and how often they should be taking them, and this in turn impacts how we design some services. While we have already seen some work around better educating patients on how they might manage flare-ups, still more could be done around patient pathways. For example this might include follow-up calls to patients two weeks after starting a new treatment, to talk about how their medicines are working and how they are feeling.

“ The key challenge we face overall remains that of ‘meeting need’ – the question of how to manage resources so that patients get the appropriate level of care ”

An important aspect of medicines optimisation is engaging and talking to patients and while rheumatology generally performs well when it comes to involving patients in decisions about their care, this is still one area the health services as a whole could improve. There is a genuine desire to make progress here, but while national frameworks can influence this, much also depends on the local approach, such as the use of patient advisory groups on pathway design, where even relatively small changes can improve this considerably.

The benefits of multidisciplinary teams are well recognised, especially when trying to help people to remain in work. While it can sometimes depend on the prevailing attitudes, in my experience rheumatology has also done well in setting a good example, bringing together pharmacists, specialist nurses, medics, occupational- and physiotherapists, and likely a named contact for social services. However, even more could be done with pharmacist-led clinics around continuing care, with specialist nurses, including around prescribing combined with other treatments. Rheumatology nurses can play an important role here – they understand their patients and work closely with their consultants.

Other changes in future might include outreach clinics – seeing patients in their own GP setting, with shared care approaches to disease management and with other therapies. And despite many improvements, the split between monitoring and

prescribing treatments between the hospital and GP surgery means there is still role for GP education on rheumatology, for example talking to GPs about the impacts of drugs. One approach might see joint clinics where the GPs and hospital can work together and share knowledge and expertise. While NHS England can support initiatives, there is also a role for industry to help publicise and share best practice, including on pathways and patient reviews.

In the wider perspective, the key challenge we face overall remains that of ‘meeting need’ – the question of how to manage resources so that patients receive the appropriate level of care. But while clinicians may be the experts in treating a disease such as RA, they could also learn a thing or two from patients themselves – spending more time with the people who are experts in living with it. Organisations such as NRAS can play a vital role here, sharing their insights and understanding with professionals to work towards a healthcare system that supports the best outcomes for people living with rheumatoid arthritis.





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