

Resource

## Keep taking the pills

Adherence is often easier said than done. In broadest terms it is defined as “the extent to which a patient’s behaviour follows medical advice”, and whether it relates to taking medication, following a diet, or adopting lifestyle changes, there’s no doubt that it can require psychological stamina.

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The critical importance of adherence in the management of rheumatoid arthritis

The vocabulary may have moved on from compliance (or concordance) which, in the era of increasing patient involvement in decisions and a more collaborative approach to care, now seems judgemental and implies obedience – is something with which we all still struggle. For chronic disease in general,

the best evidence suggests that patients take their treatment only half of the time, and for patients with RA, that figure varies between 30% and 80%. To make matters worse, such difficulties often go unreported or unnoticed. Patients often feel reluctant to admit to non-adherence, fearing disapproval, and studies suggest that physicians are bad at asking about it, assuming that a failure to respond to therapy requires a medication change, rather than a frank discussion. In addition, a recent study has suggested that doctors can only reliably identify those patients who do take their medications rather than those who don't, thereby failing precisely those who need the most support. The result? Sadly, the evidence is unequivocal, the success of RA therapy hinges on adherence – and patients who don't take their treatment run the risk of flares of disease and continuing pain and stiffness, joint damage and disability. Recent studies have shown that disease activity scores (DAS28), inflammatory markers (ESR and CRP), x-ray damage and functional impact are all significantly lower in patients with good adherence to treatment. Better adherence should mean better quality of life, but we must accept that sometimes it's a tall order.

Patients may struggle with DMARDs intermittently or constantly, and for very different reasons, but non-adherence generally divides into unintentional or intentional patterns. Unintentional non-adherence is often either due to physical difficulty with or simply forgetting, to take medications. On one level, these may be the easiest issues to overcome, and there are 'tricks' that patients can use such as reminder alerts on mobile phones or, for the less e-minded, sticky-notes on bathroom mirrors or fridges. One of my patients wraps a "horrendous pink hair-band" round her toothbrush – whatever works to jog the memory. With the commonest DMARD, methotrexate, where adherence to weekly medication can be difficult, adopting a habit of Methotrexate-Monday (and Folic Acid-Friday) can make a big difference. Difficulty with physically taking tablets or injections can also be troublesome, but specialist nurses are often able to help and advise in this regard.

Unfortunately, the more difficult type of non-adherence is intentional. This signifies a concrete decision not to take medication, and is often based on personal beliefs around the balance between the need for the drug and the perceived risk, side effects or thoughts and fears about taking it; sadly DMARDs often lose out in this risk-benefit analysis. It's sobering to think, for example, that NSAIDs are better adhered to than any of the DMARDs, including biologic therapies, as they are familiar, give immediate relief and are still (incorrectly) considered to be risk-free: "...if I can buy it from the chemist and it doesn't need monitoring, it can't be bad for me...". This intentional non-adherence is dynamic, susceptible to several influences and is understandably sometimes hard to discuss and address. Patients may not start treatment due to grief/anger at their new diagnosis, difficulty understanding the disease or its treatments, the perception of risk of treatment versus the risk of disease progression and so on. It's critical that they have the time and space (and indeed the courage) to raise and discuss these issues early when new beliefs and behaviours are being adopted. The slow onset of action of many RA drugs is an additional factor here. Later on in disease, problems might still be linked to differences between a patient and their healthcare team in the 'belief of need'. This particularly applies to patients in Low Disease Activity States (DAS 2.6-3.2) may feel that they're "actually doing ok for now" and be reluctant to increase their therapy further, although their doctor or nurse may recommend escalation in order to reduce residual disease as part of Treat To Target. Without honest dialogue at every stage, and by all parties, valuable opportunities are lost.



**A pictorial representation of the challenges facing adherence to DMARD therapy**

Intentional non-adherence depends on the balance between perceptions of risk, the need for treatment and side effects; non-intentional non-adherence usually relates to physical ability and forgetfulness

Greater understanding of the risk factors for non-adherence might allow for better support for those who are really struggling to take their DMARDs. The main factors associated with non-adherence are socioeconomic and healthcare factors (especially a poor doctor-patient relationship), condition and therapy-related (complexity of treatment and side-effects, both feared and real) and patient-related (beliefs and the presence of other psychological factors, particularly depression). However, as with everything else in RA, there's no 'typical' patient or risk profile – although as expected, a recent study

has highlighted that patient's beliefs about the necessity for treatment and a good doctor-patient relationship are crucial. Most patients with RA actually do have positive beliefs about the necessity of their medication, but levels of concern about side effects are also high (particularly when treatment requires regular blood tests to monitor for side effects), and perhaps it's human nature to recall most profoundly the one bad story about treatment in the face of several better ones. In general, if the feeling of necessity outweighs their concerns, patients will take their medication – until such time as their perceptions change, and then a different psychological landscape will need to be negotiated.

However, recognition of the problem, both by patients and their healthcare team, is half the battle, and an honest and open dialogue about difficulties with adherence at all stages of disease is crucial. Patients need to realise that they are not alone. They should feel empowered to recognise why they are struggling and to find the courage to articulate the concerns that dominate their treatment decisions; seeking help from family, friends, GPs and NRAS can be invaluable here. Healthcare professionals also need to ask the right questions and be flexible and open-minded about the answers they get. Sometimes the simplest solutions really are the best, and support can go a long way to changing negative beliefs, thereby improving adherence and outcomes for patients with RA.

## Medicines in rheumatoid arthritis

We believe it is essential that people living with RA understand why certain medicines are used, when they are used and how they work to manage the condition.

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