Condition Insight Reports

For Clinical Staff

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Rheumatoid Arthritis (RA)

Overview of the health condition or disability

What is the condition usually called?

Rheumatoid arthritis (RA), a type of inflammatory arthritis (IA). Occasionally people with (adult) juvenile idiopathic arthritis (JIA) will describe themselves as having RA.

What is the generally preferred term when referring to someone with this condition?

We do prefer to say ‘people living with rheumatoid arthritis’ to ‘sufferers’ or ‘patients’.

Commonly reported variability in functional restrictions

Do people with this particular health condition or disability find its impact on daily life can vary from time to time?

Yes, significantly.

What aspects of daily living can be worse and what might be constant?

Different patterns of RA produce differing pictures of functional restriction. In the early stages sufferers are likely to be largely unimpaired except during flare ups, but if the disease progresses and joint destruction develops the impairment is likely to be more severe and constant.

Even when optimally controlled by medication, an underlying level of the disease tends to be there all the time, but the degree of symptoms varies. Stiffness tends to be worst in the morning, when it is common to take more than half an hour to relieve. Flare ups of the condition, when particular joints are swollen and tender, can come at any time, but more commonly when the condition is poorly controlled. These can last for days or weeks.

If someone with RA has had a joint replacement then the limitation to function will be constant regardless of condition state and this should be considered.

Presenting symptoms

Can include, but not limited to:

- Pain
- Stiffness (especially if early in the morning)
- Swollen joints (not always visibly swollen)
- Fatigue
- Flu-like symptoms
- It is important to remember that where there is both upper and lower limb involvement, the combined effect of the functional restrictions may lead to greater mobility and care needs.

Lower limb – mild functional restrictions:

- People with this level of functional restriction would not have any noticeable disabilities on an everyday basis. Pain, discomfort, joint swelling and/or stiffness will often be low grade or minimal, and normally wears off quite quickly as the person ‘limbers up’ in the morning. Although there may be exacerbations, these would be infrequent and not occur on a regular basis. A person with mild restriction would normally have no physical difficulty in getting around and would normally be able to dress independently and put on socks and shoes, using simple technical aids if required. The ability to rise from sitting, attend to own toilet needs, maintaining personal hygiene and preparing a main meal would not be impaired to any significant degree. They would have little or no functional limitation on a day-to-day basis arising from any symptoms.

Lower limb – moderate functional restriction:

- People with this level of functional restriction may experience persistent swelling (effusions) of their hips, knees, ankles and/or feet. Deformity of some or all of these joints may be present. There may be instability of one or both knees. Pain and joint stiffness would be present on rising in the morning, or following prolonged inactivity, for up to one hour. However, there may be periods of ‘flare-ups’ when increased help is needed with self-care. A ‘flare-up’ typically lasts between 10 to 14 days.

- A person with moderate restriction may have significant difficulty getting around in terms of distance due to an abnormal gait, walking stiffly and with a limp.
- They will be unable to walk at normal speed. Such a person may need physical assistance from another person in getting around. A person with moderate restriction may have difficulties with getting out of a normal height chair, out of bed, rising from a toilet and getting out of a bath. These problems would normally be most severe after resting.
- The use of prescribed assistive equipment such as a raised chair, a raised toilet seat or grab rails may help to reduce these difficulties. Such a person may have knee instability, which could indicate risk of falls, though use of prescribed assistive equipment such as a stick may help to reduce this.

Lower limb – severe functional restriction:

- People with this level of functional restriction would have gross lower limb joint deformity and restriction of joint movement. They may be on the waiting list for hip, knee or ankle replacement surgery, or for surgery to correct foot and/or toe deformities. Pain and/or stiffness would be present for up to two hours after rising, and may affect the person during the night. A person with severe restriction would have joint destruction with marked deformities and weakness of ligaments, tendons and muscles. This would lead to an increased risk of falls and reduced mobility. Mobility may be impaired, with active inflammation (flare-ups) of lower limb joints. When the feet are affected, there may be severe pain on walking. If the knees and hips are involved, standing and sitting can be difficult and painful, and mobility will be restricted even further. Joint instability may also occur. Instability affecting the knee joint will lead to an increased risk of falls with restriction of mobility. A person with severe restriction would need physical assistance from another person in getting around. Such a person would need assistance from another person with dressing and washing, getting out of bed and attending to toilet needs, and to prevent falls. Help may be needed with care needs during the day for much of the time.

Upper limb – mild functional restriction:

- People with this level of restriction are unlikely to have any noticeable disabilities on an everyday basis. Pain, discomfort, joint swelling and/or stiffness will often be low grade or minimal, and normally wears off quite quickly as the person ‘limbers up’ in the morning. Although there may be exacerbations, these would be infrequent and not occur on a regular basis. They probably would not have any significant long-term care or mobility needs. A person with mild restriction would normally have no physical difficulty in getting around. Nor would they require guidance or supervision. A person with mild restriction would normally be able to dress independently, including managing buttons, and put on socks and shoes, using simple technical aids if required. The ability to rise from sitting, attend to own toilet needs and prepare a main meal would not be impaired to any significant degree. Such a person would normally be expected to be capable of maintaining personal hygiene. They would have little or no functional limitation on a day-to-day basis arising from any symptoms and would not need supervision or watching over.

Upper Limb – moderate functional restriction:

- People with this level of restriction may experience persistent swelling (effusions) of their fingers, shoulder, elbow and/or wrist. Deformity of some or all of these joints may be present, together with reduced range of movement. Pain and joint stiffness would be present on rising in the morning, or following prolonged inactivity, for up to one hour. Painful and/or restricted neck movements may occur, but without any neurological signs (pins and needles) in the arms. However, there may be periods of ‘flare-ups’ when increased help is needed with self-care. A ‘flare-up’ typically lasts between 10 to 14 days. A person with moderate restriction would normally have no physical difficulty in getting around. A person with moderate restriction may need help with getting out of bed, and with dressing and washing. Reliance on simple kitchen aids and prescribed assistive equipment such as dressing aids or the occasional use of splints is probable. The ability to care for themselves during the majority of the day however, including preparing a meal for one, would not be significantly restricted.

Upper limb – severe functional restriction:

- People with this level of functional restriction would experience gross joint deformity and/or restriction of joint movements. They may be on the waiting list for shoulder, elbow or wrist replacement surgery, or for surgery to realign or replace a finger or thumb. Pain and/or joint stiffness would be present for up to two hours after rising, and may affect the person during the night. Painful and/or restricted neck movements may occur accompanied by neurological signs (pins and needles) in the arms. A person with severe restriction may need physical assistance from another person in getting around due to difficulty in gripping and/or holding prescribed mobility aids. They would not require guidance or supervision. A person with severe restriction would need help with getting out of bed, dressing and washing, attending to toilet needs and preparing a main meal. Due to deformity, weakness of muscles, ligaments and tendons, grip would be significantly impaired. Some people may experience further impairment of grip and upper limb function due to loss of sensation and 'pins and needles' in the arms. These problems may lead to an inability to adequately grip crutches or other mobility aids, making any mobility restriction worse. Such a person may need assistance with getting out of bed, help with dressing and washing and help with attending to toilet needs. They may need someone to assist in rising from a chair and with cutting up certain foods and with meal preparation.

Please note, due to the variable nature of this condition, some or all of the above may not be present during a face-to-face consultation, so it is important to ask what type of day the person is having and to talk to them about what a typical day is like, rather than putting too much emphasis on how they are on this particular day at this particular time.

Common areas of daily life where functional restriction occurs

What areas of daily life may a person with this particular health condition or disability find challenging?

Hands and feet are the most commonly affected areas in someone with RA, and the stiffness associated with the condition is worst in the morning or after being still for long periods (e.g. when travelling). Getting dressed in the morning and getting up from sitting or lying down can therefore be particularly difficult. Grip can be impaired, making activities that require fine motor skills challenging.

Are there any areas that a Health Professional should ask about specifically to ensure a complete report?

- The variable nature of the condition, both day to day and during a single day.
- The effects of fatigue on doing activities for long periods.
- Repetitive activity can be difficult. A task could be performed once, but might not be possible to do multiple times or might cause extreme tiredness and subsequent need to rest later in the day.
- Common effects on mental health, such as impaired cognitive function and depression, due to pain and fatigue.
- Regularity and length of flare ups e.g. how many days are 'lost' in an average month.

PIP specific questions – Where to probe at assessment:

- Does the pain increase with any activity? If so, what activity and how does this heightened level of pain effect the claimant?
- How often do they experience flare up's and how does this effect them? How long on average do flare ups last for?
- Do symptoms vary throughout the day? Is stiffness worse in the morning and then improve or is this present all day? How long does the stiffness last for?
- Do they experience fatigue? If so, probe further into this.

PIP specific – Points to consider:

- Variability – How many days on average is the claimant symptomatic?
- Reliability – Consider STAR. Due to the fatigue, swelling, deformity of limbs and high pain levels, can the claimant undertake an activity reliably?
- Pain relief – If a claimant appears to be on a low level of pain relief, ask if there is a reason for this, such as comorbidities resulting or side effects resulting in them not being able to take stronger medication.
- Informal observations – Is there any sign of swelling or deformity?
- Remember joints aren't always visually swollen so it is important to explore this with the claimant.

Common misconceptions about the health condition or disability

What kind of areas might a claimant with this health condition or disability find hard to mention or perhaps understate the importance of?

People with RA will often live with long term pain and problems with function. They will therefore often have a high pain threshold and may have adapted the way they do daily tasks, sometimes without noticing, so may underestimate the difficulty with which they do tasks.

A common example could be that someone says they dress themselves, but have stopped buying clothes with buttons, as they can't do them up, might take a long time and might have a partner helping them (e.g. with buttons, zips or bra strap).

What areas of this health condition or disability are least well understood or hardest to identify and which might impact on daily living?

The biggest misunderstanding with RA is the word 'arthritis'. Arthritis is a term more commonly given to osteoarthritis, which is caused by wear and tear, is not systemic like RA and tends to affect less joints. It is therefore crucial that the condition is not shortened to 'arthritis' by the assessor, and that they understand this is an autoimmune condition, so usually affects multiple joints and has systemic (affects whole body) symptoms, such as fatigue and flu-like symptoms.

Fatigue is often underestimated and is a common and debilitating symptom of RA.

RA is often an 'invisible' disease. Unless there are obvious deformities, someone with RA can look perfectly 'normal' despite underlying levels of pain, stiffness, fatigue and even damage etc.

Walking aids can be difficult for someone with RA, due to hands being the most commonly affected area of the body. Someone with this condition may therefore not have a walking aid, not because they don't need it, but purely because it would be too painful to put that pressure on their hands.

How is it best to ask about these areas?

Ask directly about symptoms experienced by the individual, rather than going too much on how they look.

Ask what type of day the person is having, i.e. is it a 'typical' day, or particularly good/bad? Are they having a flare-up at the moment? Have they recently had a steroid injection, which could make their condition artificially good that day?

Recommended communication approach to a claimant at a face-to-face consultation

What are the best communication approaches necessary to engage someone with this health condition or disability?

Include the person in the consultation process by asking them if there is anything that you can do to make them feel more comfortable. Let them know what to expect from the process. Ask them if they have any initial concerns about the consultation and see if you can address this. Be understanding, empathetic, patient and try not to put the individual under any pressure. Encourage them to take their time. Be aware of the person being in pain or becoming fatigued and let them know that they can have a break at any time.

Etiquette and common courtesies

Standing for long periods of time or using stairs may be difficult, so should be avoided where possible.

The claimant may be uncomfortable sitting for long periods of time so offer breaks when needed.

Basic facilities in a consultation centre should be pointed out, but in terms of the level of assistance needed or that should be offered, this would have to be decided on case-by-case, as the condition varies greatly between individuals.

Further reading:

NRAS on how to claim PIP including tips etc for people with RA: www.nras.org.uk/publications/how-to-claim-personal-independence-payment-pip

For further information including medications see NHS Conditions and Treatments: https://www.nhs.uk/conditions/rheumatoid-arthritis/

Internal reading:

Our Desktop Aids on Moving Around, Washing and Bathing & Dressing and Undressing with or without an Aid may be of use to you depending on how the claimant is effected functionally.

Our guidance sheets on Mobility in regards to the SOH and FH will also be helpful.

If the claimant reports back pain or associated disc involvement with this condition, we have fact sheets on Back Pain and Prolapsed Intervertebral-Disc which can be found on Totara.