



Time2Work

Module 2:

Support materials for people who are already employed when they develop a rheumatic and musculoskeletal disease

To disclose or not to disclose

Whether or not you disclose your condition to your employer, manager or co-workers is ultimately up to you to decide. This document looks at some considerations you may want to think about or discuss with family, friends or someone you respect and trust.

When you are first diagnosed with an RMD, time is of the essence. Work adaptations could be put in place at this point to help prevent joint damage, avoid fatigue and work burn out. If you are unable to continue to meet the demands of your job, it may result in work disability and the need to cease work before retirement. Disclosing early will allow employers and co-workers to support you at this crucial stage.

Some employers are committed to employing people with disabilities – look out for positive statements on disability or equal opportunities. Employers that have equal opportunities policies demonstrate they employ without prejudice.

Anyone with an ongoing illness may qualify for protection against discrimination. There are various descriptions of disability. The Convention on the Rights of Persons with Disabilities states, Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis

with others. [Convention on the Rights of Persons with Disabilities \(CRPD\)](#). The World Health Organisation (WHO) published the International Classification of Functioning (ICF) (WHO, 2001), which defined disability as a complex interaction between a person (with a health condition) and that person's contextual factors (environmental and personal factors), thus proposing a biopsychosocial approach to disability, viewing this as a multi-faceted process (Engel, 1980 ; Mosey, 1980). Therefore, it simply suggests that disability is a multifaceted concept and mainly driven by the social and environmental factors. **[NATIONAL ORGANISATION TO INSERT NATIONAL DEFINITION].**

Depending on the severity of your condition and disability, there may be physical manifestations of your rheumatic and musculoskeletal disease (RMD) that make it impossible to hide. In this case you may have to inform your employer about your condition and what this means in terms of what you can do. This gives you an opportunity to discuss how you could manage and/or adapt your work for your condition, for example by flexible working or with possible workplace adaptations (see *Adapting the Workplace* for more information).

If your condition is not obvious and your symptoms are not severe and/or are well controlled, you will face the dilemma of many other people with RMDs, whether or not to tell your employer and/or co-workers about your condition. In an ideal world you should feel comfortable about saying you have a RMD that may require you to occasionally take some time off work for a hospital appointment or treatment, or to work flexibly when you have a flare and/or that you may need to have some workplace adaptations. The reality can be very different. Many people with RMDs do not want to disclose their condition if they don't have to, because they want to feel like everyone else and don't want to be discriminated against because of their condition.

A number of people with RMDs put so much effort into keeping up appearances at work that they have no energy left for their home and social life. Whilst work is important on a number of levels, not least financially, it is also important to consider your quality of life in general. Through considered disclosure it may be possible to negotiate a way of managing a work / life balance in a way that is agreeable to both you and your employer.

Consider also presenteeism – this means coming into work while physically or emotionally unwell. Your ability to function physically may also impact your mood, motivations and confidence in undertaking your work and productivity, leading to absenteeism – having to take time off work. Prolonged absenteeism could lead to loss of work. You may also be affected by other factors that impact your work performance, including environmental factors such as difficulties using public transport or mobility issues, as well as personal factors such as being able to afford childcare.

Disclosing your condition may also be helpful in addressing these issues. If you need to request 'reasonable adjustments' and have not declared your RMD an employer could be justified in failing to make adjustments for you.

Reasonable adjustments include aspects of your working arrangements, such as the building or place of work or your working hours, that might put you at a substantial disadvantage compared to a non-disabled person doing the same job. There is no certainty about what is or is not reasonable, but the cost and difficulty in making the adjustments and the size of the employer will be taken into account. Reasonable, but generally inexpensive adjustments might include:

- Allowing time for medical appointments or treatment
- Flexible working hours, e.g. starting later to allow for morning stiffness
- Working from home
- Providing car parking space close to work
- Adjustments to your work station etc.

[NATIONAL ORGANISATIONS TO INSERT NATIONAL LEGISLATION]

See also fact sheet, *Adapting your workplace*

Do you need to disclose your RMD?

Legislation, policies and services available vary greatly from one country to another. However, it is important to understand what workplace legislation, policies and services are available to help you remain in work.

You do not have a legal requirement to *volunteer* information about your condition, unless:

- It is required in your contract of employment
- Your RMD might affect your or your co-worker's health and safety

You may be asked a direct question on an **application form or medical questionnaire**. If you give false information about this, and an employer finds out the truth later, you could risk losing your job.

You will be in a much better position of trust if you provide details of your condition to your employer or manager. Also, if you don't let people know you have a problem, they can't help you.

Other advantages to telling your employer or manager about your RMD include:

- It can be a strain on you hiding your symptoms and it may be a relief to disclose your condition
- In the UK if your employer or manager knows about your RMD they should make reasonable adjustments for you, if you satisfy the definition of a disabled person under the UK Disabled Discrimination Act

See also fact sheet, *Talking to employers and managers*

Choosing to disclose your condition

People with RMDs usually feel more comfortable about disclosing their condition if they feel their employer, manager or co-workers would be supportive. If they are supportive you will also experience less workplace stress. Their attitude may in turn depend on the attitude of the person with the RMD. People will always be more willing to help someone who is trying – and this applies to everyone, not just people with RMDs! Employers, managers and co-workers will generally not react so well to someone who is constantly complaining, or who they think is taking more time off than they need.

This is why good communication is vital. Although it may not be easy, you need to be able to explain your health problems in a way that is as unemotional and factual as possible and offers some positive solutions to your situation (*See also Talking to Employers and Managers and Talking to Co-workers*).

General rules for talking about your health to employers, managers and co-workers

When you talk about your RMD, here are a few simple points to consider.

- **Don't go into too much detail about your disease and use medical language, tell people only what they *need* to know** – many people do not want to be given medical details, only discuss the aspects of your condition that may affect your work and how you can work with them to find solutions
- **Try to be positive (even when you don't always feel that way) about your disease and offer solutions** – If you are really not able to cope with your work you may need to look for other solutions or consider alternatives. Some useful ideas are listed below:

Simple things you could say about your condition to explain it and how it affects your work are:

- There are many different types of RMD that involve inflammation of the joints, but some are systemic diseases, meaning they can also affect other organs
- Most people with an RMD will experience pain and may have difficulty moving around
- RMDs may also cause loss of strength and grip, stiffness and fatigue, which can make some daily tasks difficult
- Pain may be felt in other parts of the body, not just the affected joint
- For the majority of people, there will be some good days and some bad days
- Most people with RMDs experience early morning stiffness in their joints, therefore they may find it more difficult to function at this time and might therefore benefit from flexible working hours that allow them to start work later

Be selective in what you say and only mention what applies to you.

You do not have to discuss your condition with your employers or co-workers unless it affects your ability to work and, the health and safety of others. If you do discuss it, **be positive and try to offer solutions!**

If your employer or co-workers persistently ask questions and want to know more about your RMD, you can politely say that you do not wish to discuss details of your condition. If you wish to explain this a little further, you could also add that you do not think it is relevant to your job / do not wish it to impinge upon your work or how people at work treat you / do not wish to make it a big deal or focus in your life. If they do genuinely want more information, the best thing to do is to point them in the direction of your national patient organisation's website or the relevant national health department website on RMDs. They may even find out more about how they can provide support!

Supporting references

Hammond A, O'Brien R, Woodbridge S, Bradshaw L, Prior Y, Radford K, Culley J, Whitham D, Piliakottil- Jacob, R. (2017) Job retention vocational rehabilitation for employed people with inflammatory arthritis (WORK-IA): a feasibility randomized controlled trial. BMC Musculoskeletal Disorders. <https://doi.org/10.1186/s12891-017-1671-5>. Available on: <https://bmcmusculoskeletdisord.biomedcentral.com/articles/10.1186/s12891-017-1671-5>

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