



Time2Work

Module 1:

Support materials for young people entering the workplace for the first time

For most people with rheumatic and musculoskeletal diseases (RMDs), it is important to undertake paid work despite of their condition.^{1,2,3,4} However, it can be hard to find a balance between paid work and everyday life in general.^{4,5,6}

If you experience problems in your job, you can try to talk to your employer or someone else who is responsible for the work conditions at your work place. There may be some small changes in your work conditions, which can have a huge impact on your abilities to manage your job. There may also be possibilities for support through your community services.

How your doctor and healthcare team can help

Your doctor and healthcare team have a significant role to play in helping to keep you as healthy and independent as possible. However, your doctor may not fully understand why the ability to work is so important to you, in which case you may need to take some active steps to address the issue with him or her:

- If you have not already done so, plan ahead how you are going to introduce your commitment to entering the workforce into your next consultation
- Make a short list of the reasons why you want or need to work and what kind of support you would like from your doctor and healthcare team
- Ensure your doctor clearly understands your plans to enter the workplace. Discuss the type of activities this might involve and how it fits with your disease
- If you plan to study or change job, you can share your interests and plans with your doctor and healthcare team and discuss what is possible for you in your current situation

Your doctor may be able to refer you to other members of the healthcare team, such as a physiotherapist or an occupational therapist for an assessment and practical help with making work related adaptations.⁶ Depending on the country you live in, the employment services in the community may ask your doctor for a comprehensive report regarding your ability to undertake paid work. In that case, it is important that you provide information about the specific tasks/positions/working hours that may cause you problems.

Keeping your RMD well managed is important for your independence and ability to work. Talk to your doctor about the most appropriate and effective pharmacological treatment and talk to your healthcare team about what else you can do to help yourself. Find out about national and local organisations that may be able to help and support you including career advisers and organisations for people with RMDs.

Doctor and hospital appointments

Some doctor and hospital check-up appointments will be set in advance, so you can give potential, or new employers plenty of notice about when you will need to take time off. This is very helpful to employers/managers and co-workers, as it allows them to plan ahead and cover the time you are away from work. Unfortunately, RMDs are not always predictable, so you may also need to talk to your employer about the risk of a flare and the need for unscheduled appointments.

Managing expectations when you have a flare

If you choose to work, you need to make it clear to your doctor that you want to be ready to work as soon as possible, or to return to your new job as soon as you are ready. You may need sick leave in a period if your arthritis is active. This may be when diagnosed at times when your medication is not fully effective i.e. when pausing your medicine or changing to a new drug. You can ask your doctor whether he or she can estimate when you can expect to be able to work again so you can inform your employer.

It is important that you give yourself time to fully recover from a flare, so don't go back to work too soon. On the other hand, you may feel that you can manage to do some work from home or return to work gradually by working for a limited number of hours or days a week to start. Use your own experience of your condition and advice from your doctor/members of your healthcare team to help you assess how much you can take on and discuss with your employer how soon you can return to your normal level of activity.

For some it is difficult to share with colleagues and employer that you have a chronic disease due to worries about being stigmatised and the relation to co-workers may be strained. It can be difficult for colleagues to understand that you may feel pain and fatigue as it is invisible.^{4,5} Written pamphlets and open dialogue about your condition will help over time.

Dealing with pain, fatigue and morning stiffness

Despite the constant development of new pharmacological and surgical treatments, many people with inflammatory arthritis (rheumatoid arthritis, psoriatic arthritis or spondyloarthritis) still experience problems with pain, fatigue, reduced mobility and psychological distress in their everyday lives.^{1,2,3} Between 35 and 40% of patients with rheumatoid arthritis experience stress, anxiety or depression.⁷

Pain is the most common symptom of RMDs and managing pain can be one of the hardest things to achieve. Make sure that the activities you perform in your job are not exacerbating your condition and causing pain. You may be able to alleviate any stress to your body by adapting your workplace or the way you work. Your doctor may be able to refer you to an occupational therapist who can help you with work adaptations.⁵ Some larger employers may have occupational health departments that can help you with work assessments and adaptations. In some countries, it is possible to get an occupational therapist from the community service to visit your work place to assess relevant changes – ask for options in your region/local community.

If your job is sedentary, make sure you take regular stretching breaks. A physiotherapist or an occupational therapist may be able to recommend exercises you can do at your desk or workstation to help prevent stressing your joints by repetitive movements and keeping your joints mobile. Physical activity and exercise after work is important for you to be able to continue to fulfil the physical demands at work.

If you find it hard to manage your pain, discuss treatment options with your doctor or specialist. Keeping a pain diary or using a pain monitoring app to map when you are having most pain and any exacerbating factors may be useful to bring at your next consultation. Ask them about options of pharmacological and non-pharmacological treatment. These can be alternative types and combinations of painkillers, the use of heat and cold packs, and psychological support to help manage your pain.

Fatigue is another common problem that may affect all areas of life.⁸ Fatigue is associated to i.e. pain, physical inactivity, depression, obesity, and poor sleep. Fatigue may affect concentration, problem solving, memory and your motivation to socialize and thus may impact your work ability.⁸ Starting something new is always tiring, as there is so much to think about and take in. Expect to feel more tired when you start a new job.

If you find that your work takes all your energy and that you are exhausted when you get home, assess if there is anything you can do to make your work or commuting to work less tiring. You may also consider whether there are tasks at work and after work you can avoid or ask for help to fulfil.

Physical activity can lower your fatigue level.^{9,10} It can be exercise at moderate intensity, but even a reduction of sedentary time can reduce the severity of your fatigue.¹¹ Also, cognitive behavioural therapy can help ease your fatigue.^{9,12} It is important to try to maintain a good balance between your work and home/social

activities. You can try to keep a diary of your fatigue level and your activities for a couple of weeks and reflect upon whether there are patterns to learn from by looking at the days you felt less fatigued and days where you felt totally exhausted.¹²

Your sleep at night can also affect your fatigue level as well as mood and pain and many people with inflammatory arthritis experience problems with sleep.¹³ Light to moderate physical activity can contribute to a better sleep quality.¹⁰ Avoid physical activity close to bedtime. If you do not sleep well, or you are feeling more fatigued than usual, your doctor or nurse may be able to help.

Morning stiffness affects many people with RMDs. If you have severe morning stiffness you might consider asking an employer if it is possible to start work a little later and work a little longer to make up the time. Some employers offer job sharing and shift work, see if this is an option.

Heat or a hot shower may relieve morning stiffness. Ask your doctor, physiotherapist or occupational therapist if they can recommend any exercises or other strategies to help relieve morning stiffness.

Overcoming anxiety, stress and low moods

Looking for a new job and starting a new job can both lead to anxiety and stress, which can have a negative impact on your symptoms.

If you are feeling out of control, lacking in confidence or feel unsupported, this may affect your mood. It is easy to say, 'keep positive', but sometimes it is easier said than done. You may find you are able to deal with low moods yourself and with support from your family and friends, but if you are experiencing severe and/or persistent anxiety, stress or low moods, do go and see your doctor.

There are a number of techniques that you may use to help you build confidence and improve your mood, such as relaxation and cognitive behavioural therapy. You can reflect on what triggers anxiety and low confidence and what you feel helps. Ask your doctor if he or she can suggest any techniques or programmes to help you relax or refer you to the appropriate specialist or therapy.

In many countries, self-management courses are available to people with RMDs. Your healthcare team may be able to recommend one or provide you with the contact details for a support group that runs such courses.

Improving your consultation

Most doctors and nurses have limited appointment times, so it is important that you make the most of your consultation:

- Keep a note of your physical and emotional symptoms and any exacerbating factors
- Keep a note of medications and treatments – include prescribed medicines and therapies, medicines you buy from the pharmacy and complimentary treatments and therapies

- Make a list of questions you want to ask your doctor about your condition, medications, treatments, therapies and options for support in the community
- Inform your doctor about how your condition affects your everyday activities and ability to live independently, including any work-related issues

Supporting references

- ¹ Lutze U, Archenholtz B. The impact of arthritis on daily life with the patient perspective in focus. *Scan J Car Sci.* 2007;21(1):64-70.
- ² Kristiansen TM, Primdahl J, Antoft R, Hørslev-Petersen K. It means everything: continuing normality of everyday life for people with rheumatoid arthritis in early remission. *Musculoskeletal Care.* 2012;10(3):162-170.
- ³ Kristiansen TM, Primdahl J, Antoft R, Hørslev-Petersen K. Everyday life with rheumatoid arthritis and implications for patient education and clinical practice: a focus group study. *Musculoskeletal Care.* 2012;10(1):29-38.
- ⁴ Feddersen H, Mechlenborg Kristiansen T, Tanggard Andersenn P et al. Juggling identities of rheumatoid arthritis, motherhood and paid work – a grounded theory study. *Disabil Rehab.* 2018;1:1-9.
- ⁵ Lacaille D, White MA, Backman CL, Gignac MA. Problems faced at work due to inflammatory arthritis: new insights gained from understanding patients' perspective. *Arthritis and rheumatism.* 2007;57(7):1269-79.
- ⁶ Hoving JL, van Zwieten MC, van der Meer M, Sluiter JK, Frings-Dresen MH. Work participation and arthritis: a systematic overview of challenges, adaptations and opportunities for interventions. *Rheumatology (Oxford, England).* 2013;52(7):1254-64.
- ⁷ Cunha M, Ribeiro A, André S. Anxiety, depression and stress in patients with rheumatoid arthritis. *Procedia - Social and Behavioral Sciences.* 2016;217337-343.
- ⁸ Primdahl, J, Hegelund, A; Lorenzen, AG et al. The experience of people with rheumatoid arthritis living with fatigue: a qualitative meta-synthesis. *BMJ Open* 2019; Accepted Jan 16th, E-pub March 21.
- ⁹ Cramp F, Hewlett S, Almeida C et al. Non-pharmacological interventions for fatigue in rheumatoid arthritis. *The Cochrane database of systematic reviews.* 2013(8):Cd008322.
- ¹⁰ Løppenthin K, Esbensen BA, Østergaard M et al. Physical activity and the association with fatigue and sleep in Danish patients with rheumatoid arthritis. *Rheumatol Int.* 2015;35(10):1655-64.
- ¹¹ Thomsen T, Aadahl M, Beyer n, et al. The efficacy of motivational counselling and SMS reminders on daily sitting time in patients with rheumatoid arthritis: a randomised controlled trial. *Ann Rheum Dis.* 2017;76:1603–1606.
- ¹² Hewlett S, Almeida C, Ambler N et al. Reducing arthritis fatigue impact: two-year randomised controlled trial of cognitive behavioural approaches by rheumatology teams (RAFT). *Ann Rheum Dis.* 2019;78:465–472.
- ¹³ Irwin MR; Olmstead R; Carrillo C; Sadeghi N; FitzGerald JD; Ranganath VK; Nicassio PM. Sleep loss exacerbates fatigue, depression, and pain in rheumatoid arthritis. *SLEEP.* 2012;35(4):537-543.