

EMPLOYEE ADVICE

TOP TIPS FOR RARE EMPLOYEES

GUIDANCE FROM OUR RARE COMMUNITY:
HOW TO THRIVE IN EMPLOYMENT AND HOW TO GET THE MOST FROM
YOUR WORKING LIFE

1 Be honest

Opening up about our limitations can be scary, but honesty really is the best policy. It's important to establish a clear communication channel with your employer from the start which will help them understand how best to support you.

2 Flexible working

If your company doesn't offer it as standard, try to negotiate a flexible arrangement to allow working from home and flexible hours. This will make sure you can deliver your best across the week at times that work in with your health needs.

3 Be prepared

If you have scheduled appointments try to factor these in with your deadlines and meetings. Keep communication lines open and use a team calendar to let your team know when you are not contactable and when you are. If you know you will need a few calm days after an appointment or procedure try to get the difficult or pressing tasks out of the way before.

4 Be kind to yourself

Living with a rare disease is a different experience every day. Pain levels, fatigue, lots of hospital visits - planned or unplanned. It's hard work! Remember to move and stretch and practicing mindfulness can be greatly beneficial. Learn to accept that you are doing your best.

5 Don't take it home

Leaving your work life at the office can be difficult if you work from home so try and set yourself up a dedicated workstation that you can leave when you are finished. Keep good time records so you know that you are meeting and not going over your hours. If you are struggling with your workload talk to your employer to find a solution.

6 Set goals

This is important for two reasons. Firstly, brain fog, pain and exhaustion are horrible - goals and task setting are a crucial way to keep you on track. Secondly, even small wins can be a great motivator.

7 Make connections

Swapping ideas is always helpful. People with different rare conditions face a lot of the same challenges, networking with others can teach us new tools and tips. Check out the Rare Revolution Magazine community Facebook group as a place to start. Reach out.

8 Know your rights

Unfortunately, not every employer will be understanding. It's important to know where you stand legally if your employer is not making the necessary adaptations you need or tries to put you in a difficult situation.

9 Ask for help

Whether that be from your employers, colleagues, family, friends, or partner don't put off asking for help if you need it. Prioritising your health is important so don't suffer in silence. Communication is key and you will find people will be more than happy to give a helping hand.

10 Find your passion

Finding a career that's a great fit for you makes life a lot easier. Don't be afraid to try something new. Whether that means starting your own business or taking on a new role give it a go and find your passion.

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MAGAZINE

Produced by the [#RareRevolutionaries community](#) - A Rare Disease Collaboration on behalf of Rare Revolution

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