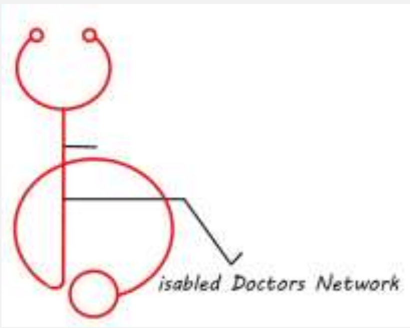

Fluctuating, Relapsing and Remitting Conditions

Document contents

- Introduction & definitions
- The size of the problem at work
- Reasonable adjustments
    - Obtaining reasonable adjustments
    - Considerations when requesting adjustments
        - Flexibility in your rota
        - The Bradford Formula/Factor
        - Adjustment implementation
- Specific condition related challenges
    - Invisible and fatiguing conditions
    - Conditions of minimal severity
- Summary of current difficulties for doctors with fluctuating conditions
- Summary of key advice

Introduction and definitions

Fluctuating conditions are those which do not follow a stable pattern of disability or illness or cause a fixed level of impairment. The term relapsing and remitting (R&R) may be sometimes used as if it is synonymous suggesting that all R&R conditions fluctuate.

https://www.verywellhealth.com/what-does-relapsing-remitting-mean-2564691

However, R&R conditions have distinct periods of highly intrusive symptoms and requirements for disease directed treatment and periods of remission. During remission the disease is less active and the individual may feel very well or anywhere on the spectrum from quite well to very well. Some people, such as those with post-viral fatigue for example, may have fluctuating symptoms and eventually make a full recovery without further problems. This is primarily a section on practical help rather than an academic discussion so I won't spend too long on definitions.

In this section, fluctuating will mean those long-term conditions/illnesses, physical and/ or psychological (not really divisible), that are generally systemic and cause a varying impact on an individual's ability to function. Fluctuating is here used to encompass 'relapsing and remitting conditions' in which the individual may have periods of good health (when the condition is dormant or less active but still in the background) and periods of ill-health which can be severe, disabling or even life threatening and may require substantial periods of time off work. Relapses may be associated with identifiable factors such as infection, sunlight, psychological trauma, bereavement or may be apparently inexplicable with our current level of knowledge.

Individuals with any condition or impairment will meet the legal definition of 'disabled' if they have a physical or mental impairment that has 'substantial' and 'long-term' negative effects on their ability to do normal daily activities.

Equality Act 2010: https://www.gov.uk/guidance/equality-act-2010-guidance

Also see our Homepage: https://www.disableddoctorsnetwork.com/

This means that the condition affects their private life as much as their working life, a fact which is often forgotten. There is a perception that any 'real' disability will have some visible sign or the individual will need equipment that others recognise as denoting limitation that needs help. This can make life even more uncomfortable for people with an 'invisible chronic illness/condition' when they ask for help or support. They can perceive disbelief or incredulity, some may even experience hostile 'banter.'

There is a sense in which every disability or long-term condition is a fluctuating condition. Nearly every person with a physical or mental condition that limits their movements, senses, or activities (even if it is apparently circumscribed), will experience fluctuations. Either with intervening complications such as infection (to which they may be more prone) or simply fatigue. This section concentrates on those illnesses or conditions where fluctuation is a defining characteristic e.g. bipolar disorder, depression, vasculitides,

autoimmune conditions like Multiple Sclerosis, Systemic Lupus Erythematosus, Inflammatory Bowel Diseases.

Certain conditions are recognised under the Equality Act 2010 from the time of diagnosis. These include cancers, Multiple Sclerosis and HIV.

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/570382/Equality_Act_2010-disability_definition.pdf

This makes it more likely that those living with these conditions will have fewer problems getting the support they need at work. It is hard to understand why some conditions are specifically named - best practice in supportive care would now be that 'needs not diagnosis' are the most important criteria for receiving support.

The size of the problem at work

http://www.theworkfoundation.com/wp-content/uploads/2016/11/378_FCFS_Final.pdf

Although each fluctuating long-term condition may be relatively rare, there are many conditions which fluctuate and/or relapse and remit. The problem is a common one for employees and employers. Possibly because these conditions do not come under one diagnosis, there has been very little attention paid to finding ways in which individuals can work most effectively for their organisation whilst maintaining the best health possible.

Many cancers (another umbrella term) are becoming 'treatable not curable' leading to long-term illness, sometimes requiring courses of treatment and time off intermittently. However, the problems of fluctuation are little discussed in occupational health manuals, papers or textbooks, government or health service union policies or health service protocols (see references). Even the latest White Paper on employment for those with disabilities has about one line and nothing helpful to say on this complex issue.

https://www.gov.uk/government/publications/improving-lives-the-future-of-work-health-and-disability

Of course, there are many people who will have two or more difficulties that can affect their employment e.g their illness and that of a family member or being a single-parent and having a fluctuating condition etc. They will need even more careful support and help with planning.

Reasonable adjustments

- ### Obtaining reasonable adjustments

The specific difficulties of living with a chronic fluctuating condition are not well taught at medical school. Very little attention is paid to the practicalities of employment for those living with such an issue. This means it is essential for you to recognise the fact that you will

have to take the lead (and be sure of your rights) in getting useful reasonable adjustments, keeping them and making sure they are observed and changed when necessary. You may even have to take private advice to understand the range of options that you are entitled to in order to keep you in work rather than rely on HR, occupational health, or the BMA. You cannot assume that your occupational health clinician can give you the expert help you need or that any union support from the BMA or Hospital Doctors Association will give you a complete range of options or the right sort of support. You may need to talk to a solicitor (specialising in employment law), private occupational health physician or HR/employment organisation who are specialists in this field (or at least are prepared to be imaginative and know the law, as there is so little data) to understand your rights and options. There has actually been very little research on the lives and needs of disabled/chronically ill doctors.

Strangely, people (including doctors who do not work with people with R&R conditions) seem to have difficulty understanding that an illness is incurable and R&R and yet not visible. Doctors report being asked or told 'When you're better….' Or being asked to take on extra responsibilities when they come back from sick leave to 'make up' for being off. Of course, if you are absent and others have to take up your work (and of course, staffing levels are not adequate to cover holidays let alone unexpected absences) it will make life difficult for them. However, the organisation needs to plan as though unexpected absences will happen (as they will for all sorts of reasons). Not you cover the whole burden of being ill yourself. It is important that the department understands that your changes will apply in the long-term.

If your condition gets worse, or you have a complication related to the illness or your treatment, you may have to revise any adjustments and instigate a permanent or temporary increase. It is best to see someone you trust regularly to help you so that you can be prepared and to have thought through what you will do if things get worse.

- **Considerations when requesting adjustments**

1. Flexibility in your rota

Many people with fluctuating conditions find that flexibility in their rota or job plan can help to keep them as well as possible. Obviously during a relapse, it may not be enough but relapses are likely to be less common when you are not overworked. Flexibility and a containable workload will be more likely in a large department and where you can avoid it, don't be single-handed. There is a lot of overlap with doctors towards the end of their careers.

It is about sharing out the responsibilities of the department fairly, to everyone's mutual benefit, rather than everyone trying to do every task. If you become ill during your career you may need to consider retraining (you may need to fight to get this) as suitable redeployment is rarely offered. You need the best possible chance of earning enough to live on (another consideration that others may not think about) and the changes in the NHS

pension system in 2008 specifically militate against people with fluctuating conditions. You may feel uncomfortable about the changes you need to make, but unfortunately the system, and those who are supposed to help people with ill-health, have not made adequate provision for fluctuating conditions in rules and regulations. The government is making life very difficult for those with ill-health severe enough to have an impact on their employment - with the expectation that you will use every means to stay in full-time employment. This is not necessarily always in everyone's best interest, but is the way that current arrangements work.

2. The Bradford formula/factor

Some hospital Trusts use the Bradford formula/factor to calculate the impact of employee absence on an organisation.

https://www.ciphr.com/advice/understanding-the-bradford-factor-score/

If your organisation does not take into account fluctuating illness then it is easy to get a high score when your illness is out of control. Some even report having disciplinary action taken against them. This is where getting your illness recognised is very important. Of course unplanned, unexpected and irregular absences are difficult for departmental work. Which is why it is important to have a job plan that minimises the likelihood of relapse and the impact of these on the work of the department. Many people with a fluctuating condition can work a minimum number of sessions pretty much all the time (unless gravely ill) e.g. 1-2-3 days a week. That is if the rest of the week can be worked flexibly and not all when necessary. Some report using their holiday flexibly to make up for when they are ill - this is intensely personal and it is really better to have the sort of job plan that means that work is a contributor to health, and not a detractor.

3. Adjustment implementation

Obtaining reasonable adjustments on paper is a first step but managing to ensure that they are implemented and enforced is another matter. Many jobs have unpredictable workloads, or the workload is unremitting. You may feel obliged to take on extra work because you look all right on a day when everyone is under pressure - then the next day the same thing happens. You soon find your adjustments have gone. You may feel obliged to come in on your working at home day or day off because of an important meeting or because there is a rota gap. It is very difficult and this is where you need support. You are least likely to feel able to ask for help when you most need it and most likely to succumb to feelings that you need to do more rather than less when you are under pressure or ill. If you have good Occupational Health support that is the place to start. If you don't have this, it is time to seek support elsewhere. You could consider approaching the BMA or 'Access to Work'.

See website section Employment Support:
https://www.disableddoctorsnetwork.com/employment-support

However, some organisations may not be aware of all the options open to you and some find seeking support in the private sector can be helpful here. This is yet another reason why we need a greater focus on getting information about the needs of doctors living with chronic illness.

The degree of fluctuation or the number of relapses you experience are likely to be affected by your workload. Especially if your workload is uncontrollable and relentless over a longer period of time. Deciding to take a day off can be a very difficult decision and one day off may only bring you back to just managing temporarily. You may then find you are putting up your medication to manage to stay in work which will then cause other problems in the long-term with cumulative morbidity from drugs. There is no easy answer to these problems but understanding that the situation is difficult and that it is not some moral failing on your part that you are finding it so, is a useful first step.

Specific, condition related challenges

- Invisible and fatiguing conditions

A recent paper reviewed the characteristics of fluctuating conditions that may cause extra complications/difficulties:

- Invisibility - colleagues have difficulty believing in it
- Association with fatigue - not the same as being tired
- Incurability - this sounds strange since so many conditions are incurable but if they cannot be controlled consistently then this causes issues in the workplace until the right plans are put in place.

https://journals.sagepub.com/doi/full/10.1177/0961203318808593

Invisible chronic illnesses which cause fatigue seem to be the most difficult conditions for people to understand, including doctors and other clinicians. Onlookers can have difficulty ‘believing’ in them and unspoken attitudes or crass comments can demoralise the doctor living with the condition. It’s bad enough having the unpleasantness of the disease, the worries about your future and your finances without additional stress from interactions with colleagues, the Trust systems or others who you hope might help.

Fortunately, many doctors have excellent health and do not expect their colleagues to be ill. Everyone (or most people) will help out with a limited reduction in service but may feel resentful about long-term needs. It is in everybody’s interests for you to have a job you can do with honour and the minimum amount of time off. This may take some time and experimentation to organise.

- **Conditions of minimal severity:**

These are those conditions which are not life-threatening, which do not require long-term medication associated with serious adverse effects and which do not cause cumulative morbidity from disease activity or treatment - but do cause reduced capacity to work at times. Examples might include less severe chronic fatigue syndrome, non-severe migraine, minimal endometriosis.

It is likely that reasonable adjustments can be found and enforced as they are likely only to have minor effects on your own work or other people. You are likely to be able to work full time if you want to and you may find your condition remits with time. You may require very little time off work and it may be possible to find a niche job which enables you have the best health possible without any noticeable impact from your illness. However, always remember that without the right adjustments, your conditions could become more severe and intrusive.

Summary of current difficulties for doctors with fluctuating conditions

- Current structures for supporting disability do not recognise specific difficulties of fluctuation or relapsing and remitting conditions.
- The occupational health clinician in your organisation may not know enough about your condition or how to support people with fluctuating illness.
- Your union may not know how to support you, offer a range options or be able to negotiate a suitable system to enable you maintain your employment with the best health possible.
- Your Trust may use the Bradford formula in assessing sick leave absence which may inherently disadvantage people with fluctuating conditions.
- If you are seriously ill and cannot work enough hours to support yourself and need to retire, current Tier 2 pension rules will mean that you are penalised financially (with irretrievable loss of at least one third of your pension) if you try and work intermittently in any NHS-related employment/self-employment. This was negotiated by the Health Unions demonstrating, once again, how poorly understood the consequences of fluctuating ill-health are.
- Adjustments need to be life-long if your condition is incurable.
- Your condition may worsen over the 30 - 40 years of your career because of accumulated morbidity from the illness and/or medication.

Summary of key advice

- Get all the moral, psychological and coaching support you can to believe in the reality of your illness without self-blame and to contend with all of the unconscious bias and unthinking comments you will receive. Although these comments are often simply ignorant, they can be wearing.
- Get the very best expert help you can to ensure you are getting all of the adjustments to which you are entitled. You may have to pay privately or seek support from a lawyer to get the best advice possible. Aim to hold onto your job with the best health possible.
- You may be penalised if you retire and try to work intermittently but you may still have to retire if your health is being damaged by work.
- Do not talk to HR, Clinical Directors or anyone else whilst you are feeling demoralised or vulnerable. Wait until you are feeling a little better or more stable and take independent advice to understand your rights.