



Factsheet two

Disability, health and wellbeing

Disability, health and wellbeing

The relationship between disability, health and wellbeing

The interface between health and illness is complex in the case of disability.

Health, which is an attribute referring to an individual, can also be understood in two ways: as a diagnosis of the biological condition of the body in which any illness can be managed according to guidelines; and, in contrast, as a more holistic concept embracing somatic, psychological and social factors and their interrelationships¹.

Three points about health formed the basic components of the face validity of WHO's health measurement strategy²:

- that health is a determinant of, but does not coincide with, wellbeing;
- that health is a function of states or conditions of the human body or mind, constituted by the person's intrinsic capacity to execute specific tasks and actions in a range of domains that capture the full breadth of human functioning; and
- that health is an intrinsic feature of the individual.

It is felt by some that an important part of wellbeing is "*self-worth*". Ideally, we would look internally to our motivations when trying to define our self-worth or value but, sadly, human nature can compel us to look externally for such validation. We, therefore, often define our self-worth by how useful we perceive ourselves to be in the context of society, for example how much we are able to contribute to our communities. As doctors, we are even more vulnerable to this persuasion, tending to being highly self-critical and judging our worth in terms of achievements.

Studies have shown that individuals with disabilities are more likely than people without disabilities to report³:

- poorer overall health;
- less access to adequate health care; or
- smoking and physical inactivity.

¹ <https://www.ncbi.nlm.nih.gov/pubmed/26311804>

² <https://bmcmedicine.biomedcentral.com/track/pdf/10.1186/s12916-017-1002-6>

³ <https://www.cdc.gov/ncbddd/disabilityandhealth/relatedconditions.html>

Disability, health and wellbeing

All of these factors can mean that making a contribution to society or '*making a difference*' in a way that can be measured by others, can be far more difficult as someone with a disability compared to someone without a disability. This can subsequently have a major impact upon our sense of self-worth and value which, in turn, can negatively impact upon our mental health and wellbeing.

Persons with disabilities often are at greater risk for additional health problems *that can be prevented*. There is much evidence to suggest that people with disabilities have fewer life opportunities relative to those without disabilities. They are more likely to be unemployed or relatively under-employed, and to live in poverty than people without disabilities.

Many people become disabled in part by chronic and/or life-threatening illnesses, and many people with disabilities not caused by illness have chronic health problems as consequences of their disabilities.

All people, regardless of health or impairment, face barriers to living a healthy lifestyle. Although time and money are universally recognised barriers, a recent study found that disabled people face additional barriers that are disability related such as reliance on carers and their unique situation and needs that further impact on their ability to engage in healthy lifestyle behaviours⁴.

Disabled citizens are twice as likely to be inactive when compared to non-disabled people. A report from the UK Chief Medical Officer reviewed evidence for a relationship between engaging in physical activity and positive health outcomes for disabled adults⁵. This report also provides suggestions on the amount of physical activity for health gains - the frequency, duration and intensity of physical activity that disabled people should undertake to benefit their personal health. The report concluded that, for substantial health gains, disabled adults should do 150 minutes of physical activity at a moderate to vigorous intensity. They should also do two sets of challenging strength and balance exercises two times per week.

⁴ <https://ijbnpa.biomedcentral.com/articles/10.1186/1479-5868-10-100>

⁵

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/748126/Physical_activity_for_general_health_benefits_in_disabled_adults.pdf

Disability, health and wellbeing

Physical activity has well-known beneficial effects on health, such as a decreased risk of chronic diseases and an improved quality of life, and has also shown health-enhancing effects for people with physical disabilities⁶.

However, it can be more difficult for people with a disability to achieve an adequate level of activity and exercise, not only due to physical impairments or symptoms which make movement or exertion difficult, but also for a plethora of other reasons. As we have already identified, people with disabilities are often at a financial disadvantage due to employment difficulties. This can mean that the time needed from carers to assist with physical exercise is not affordable or that additional equipment that is needed to facilitate exercise or make exercise possible or more sustainable, is too expensive. People with physical impairments may also find it too uncomfortable using public facilities because they may need to request assistance from staff or use public facilities in a different way to people without an impairment causing attention from others or potential social embarrassment. This is assuming of course, that such facilities are accessible by people with disabilities in the first place. Many are still not.

Wellbeing and ‘the disability paradox’

“The *disability paradox*” essentially refers to why many people with serious and persistent disabilities report that they experience a good or excellent quality of life when, to most external observers, these individuals seem to live an undesirable daily existence.

This could be due to a ‘*secondary gain*’ which occurs when individuals with impairments adapt to their new conditions and make sense of them⁷. Individuals who experience disability can find an enriched meaning in their lives secondary to the disability condition.

Secondary conditions

Secondary conditions occur in addition to (and are related to) a primary health condition, and are both predictable and therefore preventable.

These might include:

- bowel or bladder problems;
- fatigue;
- mental health problems;

⁶ <https://www.ncbi.nlm.nih.gov/pubmed/29755934>

⁷ <https://www.ncbi.nlm.nih.gov/pubmed/10390038>

Disability, health and wellbeing

- weight problems;
- bone problems;
- neurological problems (e.g. dysreflexia)
- pain;
- tissue viability problems; *and*
- infection.

People with disabilities are particularly vulnerable to gaps in health care services. Depending on the group and setting, persons with disabilities may experience greater vulnerability to secondary conditions, co-morbid conditions, age-related conditions, engaging in health risking behaviours and higher rates of premature death⁸.

Accounts of wellbeing can explain why life can, and often does, go comparably well for people with many disabilities relative to people without disabilities⁹.

The nature of conditions

Important guidance on the nature of conditions satisfying the **Equality Act [2010]** on disability is given by “Equality Act 2010: Guidance on matters to be taken into account in determining questions relating to the definition of disability”¹⁰

Under the guidance, the following distinctions are made.

Progressive

“Progressive conditions are conditions that have effects which increase in severity over time, and are subject to the special provisions. These provisions provide that a person with a progressive condition is to be regarded as having an impairment which has a substantial adverse effect on his or her ability to carry out normal day-to-day activities before it actually has that effect.” (B18, p. 23)

“In order for the special provisions covering progressive conditions to apply, there only needs to be some adverse effect on the person’s ability to carry out normal day to day activities. It does not have to be a substantial adverse effect. If a person with a progressive condition is successfully treated (for example by surgery) so that there are no longer any adverse effects, the special provisions will not apply. However, if

⁸ <https://www.jstor.org/stable/3810781>

⁹ <https://plato.stanford.edu/entries/disability-health/>

¹⁰

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

Disability, health and wellbeing

the treatment does not remove all adverse effects the provisions will still apply. In addition, where the treatment manages to treat the original condition but leads to other adverse effects the provisions may still apply.” (B22)

Condition severity is an important aspect of medical conditions that can be useful for discriminating among sets of conditions or phenotypes¹¹.

A condition’s severity status might enable professions easily to identify conditions that require higher prioritisation according to needs and an allocation of resources.

Recurring or fluctuating effects

“The Act says that, if an impairment has had a substantial adverse effect on a person’s ability to carry out normal day-to-day activities but that effect ceases, the substantial effect is treated as continuing if it is likely to recur. (In deciding whether a person has had a disability in the past, the question is whether a substantial adverse effect has in fact recurred.) Conditions with effects which recur only sporadically or for short periods can still qualify as impairments.” (C5, p.29)

“For example, a person with rheumatoid arthritis may experience substantial adverse effects for a few weeks after the first occurrence and then have a period of remission. If the substantial adverse effects are likely to recur, they are to be treated as if they were continuing. If the effects are likely to recur beyond 12 months after the first occurrence, they are to be treated as long-term.

Other impairments with effects which can recur beyond 12 months, or where effects can be sporadic, include Menière’s Disease and epilepsy as well as mental health conditions such as schizophrenia, bipolar affective disorder, and certain types of depression, though this is not an exhaustive list. Some impairments with recurring or fluctuating effects may be less obvious in their impact on the individual concerned than is the case with other impairments where the effects are more constant.” (C6, p. 29)

A fluctuating condition is a chronic condition - physical or mental - where a characteristic feature shows significant variation in the overall pattern of ill health and/or disability¹².

The symptoms and experiences of people with fluctuating conditions vary widely and can be difficult to assess. Fluctuating conditions are those which do not follow a stable pattern of disability or illness or cause a fixed level of impairment.

¹¹ <https://www.ncbi.nlm.nih.gov/pubmed/27016383>

¹² <https://www.nat.org.uk/sites/default/files/implementing-the-care-act.pdf>

Disability, health and wellbeing

The issue is a common one for both employees and employers.

The needs of the economy and society have increased demands for flexible employment. Changes from standard, permanent employment relationships to non-standard flexible working arrangements have become popular¹³.

Alternative terminology

An alternative term is “*episodic disabilities*”, growing in use to conceptualise changes between disability and non-disability, but there is still reluctance to view the nature of disability itself as dynamic¹⁴.

The term “*relapsing and remitting*” may also be used at times.

An example of a ‘fluctuating disability’ is seen in systemic lupus erythematosus (SLE). A recurrent theme in the existing literature is the detrimental effect of SLE on individuals’ ability to work with higher levels of (i) disability, (ii) absenteeism and (iii) increased levels of ill-health retirement¹⁵. SLE presents specific difficulties for maintaining employment – fatigue, fluctuation and invisibility – not addressed easily by ‘reasonable adjustments’.

Sickness presenteeism can be conceptualised as occurring voluntarily (wanting to work despite illness) or involuntarily (demanding personal and work-related factors mean that the consequences of absence are too high). A recent study explored experiences of working after onset of rheumatoid arthritis, a chronic musculoskeletal disorder characterised by high rates of work disability, and concluded that workplace adjustments can facilitate voluntary ‘sickness presenteeism’.¹⁶ To reduce work disability and sickness absence, organisational policies should be sufficiently flexible to accommodate the needs of employees with fluctuating conditions.

Depression, for example, can be a fluctuating condition and this may draw into question whether it is sufficiently ‘long-term’ in order to meet the definition of a disability.

J v DLA Piper UK LLP [2010] UKEAT/0263/09/RN¹⁷ was a key case which concerned a claimant who was offered a job, but, following her disclosure of a history of depression, the offer was withdrawn. Before it could be considered whether this constituted unlawful discrimination, it had to be determined whether she met the

¹³ <https://journals.sagepub.com/doi/abs/10.1177/1044207309358588>

¹⁴ <https://www.tandfonline.com/doi/abs/10.1080/09687599.2012.662828>

¹⁵ <https://www.ncbi.nlm.nih.gov/pubmed/30451638>

¹⁶ <https://www.ncbi.nlm.nih.gov/pubmed/27927025>

¹⁷ <https://www.employmentcasesupdate.co.uk/site.aspx?i=ed5537>

Disability, health and wellbeing

statutory definition of disability according to having a substantial impairment interfering with her day-to-day life. This was under the previous legislation, the **Disability Discrimination Act [1995]**¹⁸.

Many cancers (cancer itself is another umbrella term) are becoming 'treatable not curable' leading to long-term illness, sometimes requiring courses of treatment and time off intermittently.

Many disabilities are also episodic such that individuals experience fluctuations in symptom severity. For example, individuals may report minor to severe fluctuations in wellbeing on daily (e.g., feeling worse at the end of the day), weekly (e.g., feeling worse as the week progresses), and monthly (e.g., feeling better as one recovers from treatments) cycles.

All these conditions need substantial attention in terms of care planning, as well as career guidance.

Keeping fit

We all know as doctors, that keeping fit is essential for our physical and mental health. However, it can sometimes be more challenging to exercise adequately when you have a chronic health condition or a disability.

There are a number of online resources which may help you to navigate through some of the challenges you may face when trying to exercise.

This "Help Guide" gives some advice about how to maintain regular exercise with limited mobility:

<https://www.helpguide.org/articles/healthy-living/chair-exercises-and-limited-mobility-fitness.htm>

There is also information about exercising with a disability on the NHS website

<https://www.nhs.uk/live-well/exercise/get-active-with-a-disability/>

It is also relatively easy to find videos on YouTube and the like on how to exercise with a number of different impairments. Of course, it is always wise to seek specific advice from any physiotherapy, rehabilitation or other specialist team that you may be under before undertaking these. They are often very well placed to point you in the direction of suitable resources to help you exercise regularly and safely.

¹⁸ <http://www.legislation.gov.uk/ukpga/1995/50/contents>

Disability, health and wellbeing

If you are unable to undertake anaerobic exercise for a period of time for some reason, simply keeping moving can still be hugely beneficial. Undertaking even five minutes of *Tai Chi* or *Qi Gong* per day can still provide immense benefits and many of these can be adapted to the seated position if needed.

Getting involved

Getting involved in team-based activities can be very beneficial when you have a chronic health condition or disability. A sense of belonging, being able to contribute and being accepted as an equal member of a team can have hugely positive impacts upon our mental health and wellbeing.

Becoming involved in community activities, especially in green spaces¹⁹, can have a very positive impact upon mental wellbeing, as well as providing a degree of exercise to improve physical health.

This can also provide a sense of worth and belonging. Being a doctor with a visible or disclosed long term health condition or disability who gets involved in community activities also provides a powerful role model for the community. It shows by example, that being unwell or having an impairment, does not have to lead to social isolation and exclusion. It shows the community that it is possible to belong, contribute and be active even in the presence of ill health and disability. As a doctor, this will not only have a beneficial impact upon your own health and wellbeing, but will also have a positive influence on the health and wellbeing of your own local community.

Work

It is crucial not to be excluded from opportunities at work simply because of a chronic health condition or disability. Colleagues may make assumptions about your abilities or wishes, often with the best intentions, that can then lead to missed opportunities for personal and professional growth and development.

There is no reason why a doctor with a chronic health condition or disability cannot take up senior medical or management roles. The more visible disability is in these public facing roles, the bigger the impact we have on the culture change in the medical workforce surrounding disability. It is this which is so crucial to achieving true inclusivity in the NHS.

¹⁹ http://www.ukmaburbanforum.co.uk/documents/papers/jpmh-6_3-burls.pdf

Disability, health and wellbeing

Looking after yourself

It is essential to strike the right balance between work and life for everyone. When working in a demanding career such as medicine, it is even more important. When you then consider working in medicine whilst having a long-term health condition or disability, work-life balance becomes a priority.

When living with chronic pain, fatigue, reduced independence, mental health issues, or any of the other daily symptoms that go along with having a long-term condition/disability, life becomes so much more difficult. Things that occur spontaneously without any planning for well and able-bodied people, need forethought and planning. Sleep is often affected and so can the ability to perform essential functions such as eating, drinking and evacuating bowels be. Medications have to be carefully timed in order to minimise side effects and maximise effects. Our family members are also our informal carers with the resultant changes in relationship dynamics and stress. Very few aspects of daily life that many other take for granted, are not touched by the effects of living with a long-term condition/disability.

It is generally accepted, that the impacts of having a successful medical career on family life are significant. Add into this the additional effects of a family member having a long-term condition/disability as discussed above, and it becomes apparent why a work-life balance is so important in this situation²⁰.

It is also likely, that the doctor with the chronic condition/disability, is also earning a significant proportion of the household's income. This can make finding the correct balance, very difficult indeed.

Ideally, the fact that doctors in general earn a higher salary than some other professions per annum should be used to the doctor's advantage by allowing them to reduce their working hours and responsibilities in order for them to be able to manage sustainably their chronic health conditions whilst also maintaining a meaningful career. However, the temptation is to take advantage of the salary and place your family in a situation where they can then not cope financially without it. Clearly, if a disability or condition is acquired later on in life, this situation may already exist and can then be very difficult to adjust. However, if a chronic condition becomes apparent earlier in life, it may then be possible to plan family finances in such a way that this is achievable.

²⁰ <https://www.bmj.com/content/320/7247/1437/related>

Disability, health and wellbeing

The impact of all of these complex dynamics upon the mental health of the doctor in question can be highly significant. It is always important to keep this under check. Remember to eat healthily, moderate alcohol carefully and allow yourself the occasional treat. Plan in regular activities that you enjoy and are easily able to achieve. Plan in regular activities which involve exercise and green spaces with family, friends and community in order to keep your mental health as good as it can be.

If there are times when your mental health suffers, refer yourself to NHS Practitioner Health for advice and support early on to avoid deterioration.

This factsheet is part of a series of nine factsheets on disability and practitioner health, produced jointly by NHS Practitioner Health and the Disabled Doctors Network. They have been co-authored by Dr Shibley Rahman and Dr Kelly Lockwood.