

**Health and work service workshop for long-term conditions:
Note of discussion
(The Work Foundation, London, Tuesday 15th October)**

Summary of key points

About the health and work service

- There are opportunities for the new Health and Work Service to support people with long-term health conditions return to work after a period of sickness absence.
- Long term conditions have a number of key factors in common, when looking at what affects people's ability to work. The Service needs to embrace these similarities but it must also demonstrate a good awareness and understanding of specific long-term conditions and the work limiting aspects of these conditions.
- The Service will need to take a personalised approach. It is essential that the right advice is given if it is to result in improved outcomes for individuals. The best outcome for an individual with a long-term condition may not always be to return to work. If returning to work is the best option then advice on any workplace adjustments and support measures will have to be appropriate and realistic.
- To ensure speedy and timely referrals into the service, GPs must have clarity about when is the best time to refer: for the majority of people this will be four weeks of sickness absence. For some, earlier referral could be better.
- The Service will need to have flexibility with timings for people for whom it would not be appropriate to refer at the four week point (for example, if someone is undergoing treatment). The Service should be flexible to allow these people to be referred later.
- The Service needs to signpost effectively to other support services, including support offered by the voluntary sector.
- The Service has the potential to help people with long-term conditions self manage and employees should be given the option to self refer into the service.
- The Service should involve employers where there are work-related issues. Early involvement of employers is ideal, where the individual consents.
- There needs to be rapid access to specialist advice and support, and where the Service is not able to provide/facilitate access there need to be other solutions (for example incentivising employers to buy-in services).
- The Service needs to work effectively alongside the NHS, including Allied Health Professionals. Consideration should be given to other healthcare professionals (in addition to GPs) referring people with long-term conditions into the Service.

About long-term health conditions

- People with long-term health conditions often have changing needs, due to the fluctuating and unpredictable nature of their conditions.
- They often change jobs or leave work altogether due to problems that arise in the workplace. It is important not to rush their return to work but it is equally important not to write people off or allow them to become disconnected from the workplace – most want to go back to work when they are ready, and need to for financial reasons.
- A phased return to work, reasonable adjustments and support measures are very important.
- People with long-term conditions may understate their condition and do not always see themselves as having an illness or needing support.

Why we ran this event

Macmillan and The Work Foundation ran this workshop to help the Department for Work and Pensions (DWP) with its thinking about how the new state-funded Health and Work Service can effectively support people with long-term health conditions. The event's objectives were:

- To identify the factors that affect people's ability to work with certain long-term conditions, and also identify the similarities across conditions.
- To discuss certain aspects of the Service and how these should be taken forward for people with long-term conditions. This included aspects such as: the quality of the advice, the timing of the referral, case management, and how the Service can best work alongside the NHS.
- By the end of the session, to achieve a shared understanding of how the Service needs to work for people with long-term health conditions.

The main customer base for the Health and Work Service is people who are at or expected to be off work for four weeks. It is therefore anticipated that referrals to the Service at four weeks are likely to contain a significant proportion of people with mental health and musculoskeletal conditions (which count for the largest number of people on sickness absence). This workshop was designed to generate discussion across a wider range of long-term conditions, and to take steps to identify how the Service could work for all of them.

The outputs of the workshop, including this report, will be used by DWP in taking forward the Service Specification and future work with their suppliers.

This report

This report is based on the discussion at the workshop. It reflects the conditions which were represented and discussed on the day, and is not intended to be a definitive account of all long term health conditions. It is also important to note that people experience conditions in different ways which can impact their ability to work in different ways, however the workshop aimed to identify similarities across conditions. The report refers to people with 'long term health conditions', as this was the terminology used on the day, however the report references can and should be read as 'long term conditions and disabilities.'

Format of the workshop

The workshop was split into two parts:

- Hearing from DWP about their plans for the Health and Work Service, which will be operational across Great Britain in 2014 (see [Annex A](#));
- Two breakout sessions exploring the factors that affect people's ability to work and key aspects of the new Service.

The breakout sessions involved grouping participants by condition, as follows:

- Musculoskeletal and Mental Health
- Cardiovascular and Diabetes
- Neurological (including Stroke) and Cancer
- Other long-term conditions, including Lung, ME and Chronic Pain

The event was attended by organisations representing a large number of long-term health conditions and other stakeholders involved in work and health (see [Annex B](#)). The discussions can therefore be said to be representative of the vast majority of long-term

conditions. However, some long-term conditions were not represented so further work may be needed to ensure their views can be fed into this process.

Breakout Session 1:

(i) What are the key factors that affect people's ability to work?

In their groups, participants discussed the factors that can affect people's ability to work. Each group focused on two or three conditions and used a template to allow them to list the factors that can affect each condition. They then compared factors across conditions, firstly in groups and then with all participants during the feedback session. The results of this session are included at [Annex C](#).

One group identified a number of overarching categories in which factors can be grouped:

- **Disease related factors**, which can include disease trajectory, treatment related factors, symptoms (primary and secondary), delay in diagnosis. Disease related factors can include nausea, pain, fatigue, incontinence, falls etc.
- **Disability related factors** which can include mobility and dexterity.
- **Environmental factors** which can include employer attitudes, the work environment, attitudes and behaviours of healthcare professionals, travel to work.
- **Personal factors** such as beliefs and values, financial issues, education, gender.

Whilst this report has kept to the original template, each of the identified factors has been grouped under the above four headings (to aid those for whom this grouping is beneficial).

(ii) What are the key similarities and differences across conditions?

All the groups concluded that long-term health conditions have more similarities than differences when it comes to factors that affect people's ability to work. In particular, participants highlighted the fluctuating and unpredictable nature of long-term health conditions, and the need for the Service to be aware of the changing needs of individuals with these conditions. A summary of the key similarities is captured in Box 1.

Box 1: Key factors that can affect people's ability to work, which apply to most long-term health conditions (for a detailed list of factors see Annex C)

- Fatigue
- Depression
- Cognitive difficulties
- Pain
- Reduced mobility
- Loss of/lack of confidence
- Risk of developing other conditions and co-morbidities
- Time away from work to attend medical appointments
- Employer beliefs and attitudes
- Work environment, type of work, workplace layout, workplace interpersonal relationships, working hours, perceived workplace support
- Travel to work
- Attitudes/behaviours of healthcare professionals
- Stigma and misunderstanding of the condition; Disclosure
- Age/gender
- Personal and family beliefs
- Financial issues
- Social factors

Participants highlighted a few key differences between conditions, including:

- The length of time it can take to diagnose the condition. For example: Parkinson's can take years to diagnose and can be difficult to accurately diagnose; there are issues with misdiagnosis for people who suffer from chronic pain; ME and Chronic Fatigue Syndrome (CFS) can be difficult to diagnose because symptoms are similar to other conditions.
- The trajectory of the condition. Some conditions are more progressive in nature, for example diabetes, whereas other conditions, such as stroke, have a rapid onset.
- The length of time it can take for someone to return to work after diagnosis and/or treatment.

Breakout Session 2: Key aspects of the Health and Work Service

For the second session, participants looked more closely at key aspects of the Health and Work Service, focusing on the following four questions:

- **Quality of advice:** How do we ensure that the advice given is fit for purpose for people with long-term conditions?
- **Case management:** How can the case management aspect of the Service work for the subset of people who need specialist support?
- **Timing of referral:** When might be the right time for people with long-term conditions to be referred into the Service?
- **NHS:** How can the Service best work alongside the NHS?

1. Quality of advice

What is the advice element of the Service?

Irrespective of length of sickness absence, employers, employees and GPs will be able to access, through a phone line and website, advice to assist with issue identification, adjustments and self-help for common obstacles preventing a return to work or to support employment.

The Service will also deliver advice as part of the assessment element of the Service. Except where specified, the points made below apply equally to all aspects of the Service.

Key points from the discussion:

- Those operating the telephone advice line need to understand long-term health conditions and how to access information on them. They need to take a personalised approach, as conditions impact individuals in different ways.
- The advice element of the Service (phone and website) should signpost to the voluntary sector and other key stakeholders.
- There needs to be a recognition that staying in work may not always be the right outcome.
- All advice needs to be personalised and tailored to the individual.
- Training of advisers will be important.

Participants agreed that the quality of advice given by the Service is crucial to its success. They also emphasised that the Service needs to give the right type of advice.

Awareness and understanding of health conditions

Participants agreed that anyone employed by the Service to give advice to someone with a long-term health condition needs to be aware of and understand specific conditions and

know where to go to get further information and intelligence about them. In particular, those operating the telephone advice line (the key advice component of the Service) need to have an awareness and understanding of the key factors that affect people's ability to work.

Ability to deal with mental health issues

Participants highlighted the need for advisers to have confidence and competence in dealing with mental health issues, which are common across long-term conditions, and how to access support for these.

Involving the voluntary sector

In developing the Service, DWP and its suppliers should continue to consult and involve the voluntary sector and other key stakeholders for information and advice on specific conditions. For example, most condition-specific and cross-condition organisations have help-lines, booklets and on-line information. The Service itself, when operational, should use these sources of information and advice.

Signposting to the voluntary sector

Participants also highlighted the need for the Service to signpost to other forms of support/services, including those offered by the voluntary sector.

Understanding the workplace

It was also suggested those offering advice need an awareness and understanding of the workplace/work environment. This might require more employer involvement. It was also suggested that the Service needs to understand the needs of the business, especially when offering advice to employers.

Personalised advice

Participants agreed that there is no one size fits all advice. The Service needs to have in-built flexibility so that advice is tailored to an individual's needs.

Ensuring the right outcome for each individual

Participants discussed what the right outcome for an individual might be. It was recognised that staying in work may not always be the right answer for an individual and the Service should offer advice about non paid activities such as volunteering. In addition, those offering advice also need to be able to signpost individuals to where they can go to get financial or benefits advice.

Training for providers/DWP suppliers

Another key issue raised was the provision of advice. Training programmes need to be put in place for providers/advice line operatives and the programmes should be properly developed and evaluated. DWP and its suppliers should learn from previous advice lines in terms of what has and has not worked well.

Access to specialist advice

Participants raised the issue of access to specialist advice and support. They suggested that if the Service is not able to provide access to this for all long-term conditions then more work needs to be done to try and incentivise employers to pay for specialist advice and support. It was noted that, in the 2013 Budget, the Government announced a tax exemption for employers offering their staff interventions recommended by the new Service. Participants discussed the need to consider a wide range of solutions to ensure specialist advice and support is available to those who need it.

2. Timing of the referral (for assessment by professionals in the new service)

What is the assessment element of the Service?

Once the employee has reached, or is expected to reach, four weeks of sickness absence they can be referred by their GP or employer for an assessment by an occupational health professional. This will identify all the obstacles preventing a return to work and any measures, steps or interventions that would facilitate a return to work. Recommendations for these will be included within a return to work plan that will be shared with the employee, employer and GP.

Key points from the discussion:

- GPs should refer people for OH assessment at the four week point.
- However, there will be some exceptions, particularly for some people with long-term health conditions. For example if people are undergoing treatment and are not able to return to work.
- Identification of people will be important, to ensure no-one falls through the gap.
- Earlier referral should also be considered if appropriate.
- The referral process should be flexible enough to deal with different scenarios.
- Self-referral should be an option.

Referral at 4 weeks

Participants agreed that GPs should refer people into the Service at four weeks of sickness absence unless there is a good reason not to (for example, if someone is undergoing treatment or their medication is being arranged). However, there needs to be a default position to give GPs a steer on the right time to refer.

Participants also discussed the need to make sure that no one falls through the net: awareness of the Service will be key and consideration should be given to how the Service will reach hard-to-reach and minority groups.

It was recognised that some people might not be ready to return to work at four weeks and they should not be put under any pressure to return. However, it may be suitable to refer these people in at a later date for an assessment although people may still benefit from accessing advice.

Earlier referral

Participants also agreed that the Service should be flexible enough to allow people to be referred into the Service earlier than four weeks, if appropriate. However, it was also noted that having a referral for an assessment by an Occupational Health (OH) professional shortly after diagnosis could cause the individual more stress. Early referral would not be appropriate for everyone, and concerns were raised about the Service's capacity to deal with high volume early referrals.

Personalised approach

It was also noted that the timing of the referral may depend on the condition an individual has. Conditions and the impact of treatment affect people in different ways, so a personalised approach is essential. It was not felt that a personalised approach precluded a general guideline of referral at four weeks.

Dealing with different scenarios

Linked to this, one group highlighted the need for the referral process to be flexible enough to deal with different scenarios: some people may be on their first period of sickness absence whereas others may have short term frequent sickness absence spells. It was

suggested that the four week point may be more relevant for people who are going on sickness absence for the first time.

The Service will also need to be able to make a distinction between people who have chronic conditions (which develop and worsen over an extended period of time) and acute conditions (which are severe and sudden in onset and where symptoms appear and change or worsen rapidly). The fluctuating nature of long-term conditions needs to be recognised.

Approach to referral

There was some concern about how the referral would be carried out in practice. Referrals should only be carried out in accordance with the wishes of the individual and they should not be put under pressure to return to work when they are not ready. At the moment, many people with long-term conditions return to work too early and later change jobs or leave employment altogether. DWP confirmed that the Health and Work Service is a voluntary service, and no-one will be forced to return to work.

One group discussed four different categories of conditions, which could affect the optimal timing of the referral: new chronics, acute on chronics, poorly managed chronics and people who are stable but gradually getting worse. The timing of the referral could differ depending on the type of condition. For example, new chronics would require an early referral and acute on chronics an even earlier referral as it takes longer for them to recover.

Stages and speed of referral

Participants discussed the need for different stages of referral, with one group suggesting there should be at least two stages. The first referral should happen as early as possible (ie the initial assessment) and the second referral should be for a more detailed follow up (this could be part of the 'further assessment' process). There may also need to be additional stages of referral if interventions or workplace adjustments are required. Participants also discussed the need for rapid referrals to assessment.

Self referral

Many people with long-term conditions self manage. In these instances self referral into the service might be appropriate, and should be an option.

Attitudes towards work and recovery

Participants felt that work needs to be part of an individual's recovery and needs to be an earlier part of the recovery conversation. Much of this depends on health professional's attitudes towards work and the importance the NHS places on work as a health outcome.

Additional roles for Allied Health Professionals

Participants also discussed the role of Allied Health Professionals (AHPs) and the AHP Advisory Fitness for Work Report, which helps AHPs advise employees about their fitness for work. It was suggested that consideration should be given to other health professionals, such as AHPs, being able to refer people into the Service.¹

3. Case management

Case management is the approach taken throughout an individual's time with the Service.

Key points from the discussion:

- Case managers need to help people self manage and identify whether an individual has a personalised care plan.
- Case managers should take a flexible approach and support people on a broad range of issues which affect their ability to work.
- DWP should not underestimate the support case managers might need to give to people with complex problems.
- Case managers have a key role in ensuring the right support is given to people at the right time.
- Case managers need to be able to rapidly access specialist support if needed.

Self management

An important part of the case management component of the Service will be helping people to self manage their condition and return to work. This should include giving information and advice, and signposting to further self management support (on the phone and on-line).

Personalised care plans

The case manager needs to identify whether the individual has a personalised care plan (available through the NHS).² The Health and Work Service should be able to work with any personalised care plan and the case manager should be able to use the information in the plan and look at broader needs/issues it contains (such as the individual's concerns, their well-being needs, actions and goals).

Difficulties associated with case management

Participants felt that the case management element of the Service could be more difficult and resource-intensive than expected. Some people with long-term conditions will have complex problems that require considerable support from a case manager. There were also some concerns about the knock-on effect this could have on the NHS, if the Service increases demand for NHS services. Despite these difficulties, case management was seen to be key to the success of the service.

Role of the case manager

Participants discussed various different roles for case managers. One group felt that for the Service to be successful the case manager would need to be able to influence the timing of the support given to the individual.

Participants agreed that the case manager should take a flexible approach and treat people on an individual basis (not putting people into a certain category because of their condition). It was also suggested that the case manager should help people manage their whole life, engaging and liaising with the NHS but also the voluntary sector.

In addition, participants highlighted the need for case managers to help people navigate through the health and employment system and help them negotiate support from their employer. For some people with long-term conditions, negotiating treatments will be difficult and they will need support from professionals. Consideration should be given to what role a case manager could play in these areas.

Return to work plans/reports

It was suggested that the case manager might want to advise the employee to share their return to work plan more widely, for example with secondary healthcare professionals who are involved in their ongoing care.

Several participants expressed caution that the return to work reports should not be used to sanction people. DWP confirmed that this will not be the case. The Service will not send return to work plans to DWP. The Service is also not linked to the benefits system.

Access to specialist support

A mechanism needs to be put in place to ensure a case manager can rapidly access specialist support if this is needed. Contractual arrangements will need to be in place with specialist providers and the voluntary sector. Participants asked what specialist services DWP could buy-in (see Annex A for DWP position on funding health interventions).

² Personalised care planning is aimed at all individuals with long-term conditions. It is closely related to and complements self management support. Anyone with a long-term condition can have a care plan if they want one. Further information is available at <http://www.nhs.uk/Planners/Yourhealth/Pages/Careplan.aspx>.

Need to avoid delays

Participants raised some concerns about delays in accessing support if an individual has to be referred back to their GP for interventions recommended by the case manager/Service. There needs to be a named professional who can support the individual throughout their contact with the Service and make referrals to specialist support.

Employer involvement

Participants agreed it was important for case managers to involve employers, with the consent of individuals. If employers are not involved from the start of the process then it may be difficult to get their buy-in in order to secure workplace adjustments and support measures. Participants also highlighted the additional difficulties of engaging smaller employers, who are less likely to have services in place to implement recommendations in a return to work report or the resources to accommodate adjustments and support measures. Involving employers, particularly smaller employers, before the return to work plan is agreed may help secure their buy-in.

Participants also suggested that tax incentives might encourage employers to buy-in services from the private sector.³ This would ease the pressure on the NHS which is already facing increasing demand alongside the need to make efficiency savings.

Awareness of local support

Case managers need to be aware of support options available in the local area.

Independence of the Service

The Service needs to be independent so that case managers can be trusted by employees and employers alike.

4. Working alongside the NHS

Key points from the discussion:

- There is potential for the Service to effect a cultural change in the NHS on work.
- The Service needs to find a way to work with Allied Healthcare Professionals.
- Consideration should be given to other healthcare professionals being able to refer into the service.
- Further conversations are needed with health departments and services across Great Britain about how the Service can work alongside the NHS.
- In England, an indicator on employment in the Clinical Commissioning Group Outcomes Indicator Set (CCG OIS) would help the Service achieve improved work outcomes for people with long-term conditions.

Cultural change in NHS

Participants highlighted the potential of the Health and Work Service to effect a cultural change in the NHS on work and wellbeing and encourage health professionals to have earlier work conversations with people with long-term conditions. This includes having a discussion about when the right time might be for people to return to work.

Need to engage other healthcare professionals

As GPs are set to be the primary referrers into the service, the relationship between them and the Service is key. However, participants highlighted the need for other care professionals to be engaged, including those in secondary healthcare. In particular,

³ HMT recently consulted on a tax exemption for employers offering their staff interventions recommended by the new service - <https://www.gov.uk/government/consultations/implementation-of-a-tax-exemption-for-employer-expenditure-on-health-related-interventions-recommended-by-the-new-health-and-work-assessment-and-advis>

participants again highlighted the role of Allied Health Professionals such as physiotherapists, occupational therapists and psychologists and the need for the Service to work alongside them (and the AHP Advisory Fitness for Work Report).

Other health professionals to make referrals

Participants discussed whether GPs should be the only professionals able to refer people into the Service. For example, other health professionals will be much more aware of the individual's needs and involved in their care than the GP. Consideration should be given to whether other professionals should be able to refer people into the Service.

Need for more engagement with the NHS

Participants agreed there needs to be a holistic and joined up approach to health and work issues and policies across Great Britain. However, it was acknowledged that this will be challenging due to the devolved nature of health but also due to the changes taking place in the NHS in England. Participants highlighted the need for further discussions with all health departments and services to ensure that the right links are being made with the NHS.

Some concerns were raised about the risk of increased local variation in care in the 'new' NHS in England. There needs to be national consistency in supporting people to return to work, but this will be challenging with the move to local decision-making in the NHS. Participants queried how the new Service would operate nationally and locally with the NHS.

Incentivising GPs and commissioners⁴

Participants said that GPs should be proactive in helping people with long-term conditions make decisions about their return to work and the Service would incentivise them to talk about work with their patients. However, participants felt that more work needs to be done to incentivise NHS commissioners across Great Britain. For example, in England employment is not included in the CCG Outcomes Indicator Set which is a major barrier. Participants agreed that work as a clinical outcome in the NHS would help the Health and Work Service achieve its goals of helping more people on sickness absence return to work.

Personalised care planning

The Health and Work Service should find a way to work alongside the NHS and the care planning process. Even if an individual does not have a personalised care plan, they should be having discussions with their health and social care professionals about how they can manage their condition. Therefore, the Service should identify what discussions are taking place and how it can add value to that.

Conclusions and next steps

In conclusion, participants emphasised the need for a personalised approach alongside the need to involve the individual in decisions relating to their condition, care and return to work. The Health and Work Service should help individuals self manage, improve confidence, take more ownership of their condition and of the management of their return to work. However, if there are workplace issues that are causing or exacerbating the health condition then the Health and Work Service will have to respond accordingly.

It was agreed that this workshop has made a good start in identifying key similarities across long-term health conditions, which will be useful for DWP and its suppliers in taking the Service forward. It will be important that this dialogue between Government, the voluntary sector and other key stakeholders is maintained to ensure that the Health and Work Service improves work and health outcomes for people with long-term health conditions.

⁴ This part of the discussion focused mainly on England, however the general points made about the need to incentivise NHS commissioners can be applied across Great Britain.

DWP Overview of the Health and Work Service

The Health and Work Service will:

- make independent, expert, health and work advice more widely available to **employees, employers and GPs**;
- help **employees** who have been on sickness absence for four weeks to return to work, support **employers** to better manage sickness absence among their workforce and give **GPs** access to work-related health support for their patients;
- benefit all **employers, including SMEs**, who currently have limited in-house occupational health services; and
- complement and work with existing **in-house occupational health provision** to ensure that any measures or interventions that could facilitate a return to work are implemented

Why increase access to occupational health advice?

Currently, over 130 million days are lost to sickness absence every year, negatively impacting individuals, employers and the State. Dame Carol Black and David Frost CBE's *Health at Work – an independent review into sickness absence* identified the importance of good quality occupational health advice in reducing the number of days lost to sickness absence. In January 2013 the government published its response and committed to the introduction of the health and work assessment and advisory service by the end of 2014, funded by the abolition of the Percentage Threshold Scheme (which compensates employers for high sickness absence costs).

What will the Health and Work Service offer?

There are two elements of the service; **advice** and **assessment**:

- **Advice:** Irrespective of length of sickness absence, **employers, employees and GPs** will be able to access, through a phone line and website, advice to assist with issue identification, adjustments and self-help for common obstacles preventing a return to work or to support employment.
- **Assessment:** Once the **employee** has reached, or is expected to reach, **four weeks of sickness absence** they can be referred by their **GP or employer** for an assessment by an occupational health professional. This will identify all the obstacles preventing a return to work and any measures, steps or interventions that would facilitate a return to work. Recommendations for these will be included within a **return to work plan** that will be shared with the **employee, employer and GP**.

The Health and Work Service will implement a stepped approach to the assessment process dependent on the level of need. These will include:

- an **initial (phone) assessment**: an OH professional will use a biopsychosocial approach to identify all the issues preventing a return to work and offer managed self-help. A case management approach will be used. DWP envisage that most employees will not require further assistance and that those that do can be referred for a further assessment.
- a **further assessment**: conducted when more detailed information on the obstacles preventing a return to work is required. This could be telephone or face to face and is expected to include an increased level of employer input and access to specialist advice, particularly focused on musculoskeletal and mental health conditions.

The Health and Work Service will not take on responsibility for, or fund, ongoing clinical care. When further support is necessary, the Health and Work Service will signpost to appropriate **external interventions**. The 2013 Budget announced a tax exemption for employers who fund the health interventions recommended by the Service (Macmillan recently responded to a HMT consultation on this exemption).

List of organisations who attended the event

- Action for M.E.
- Arthritis Care
- Association of British Insurers
- British Heart Foundation
- British Lung Foundation
- Chartered Society of Physiotherapists
- Department for Work and Pensions
- Diabetes UK
- EEF
- Macmillan Cancer Support
- Mind
- MS Society
- National Rheumatoid Arthritis Society
- NHS Improving Quality
- Parkinson's UK
- SANE
- Stroke Association
- The Fit For Work Team
- The Migraine Trust
- The Society of Occupational Medicine
- The Work Foundation
- University College London Hospitals NHS Trust
- University of Nottingham
- Vocational Rehabilitation Association

Annex C: Factors that affect ability to work, for people with long-term health conditions (part of the Health and Work Service Workshop report)

| Factors that affect ability to work | Long-term health condition | | | | | | | | | | |
|--|--|--|--|----------|------|--|---|--|--|--|---|
| | Musculoskeletal | Mental Health | Cardiovascular | Diabetes | Lung | ME/Chronic Fatigue Syndrome (CFS) | Chronic Pain | Neurological (Parkinson's, MS, Migraine, Epilepsy) | Stroke | Traumatic Brain Injury (TBI) | Cancer |
| Disease related factors: including symptoms and side effects of the condition and treatment | | | | | | | | | | | |
| Nausea (and vomiting) | | | Y - but depends on medication | | | Y | Y | Y – migraine. Y - epilepsy (side effects of medication and postictal – period after a seizure) Y – Parkinson's (nausea due to medication or low blood pressure) | | | Y - sometimes but not always linked to treatment effects |
| Pain | Y -wears people down; impacts on confidence people rule themselves out of employment. Pain is the biggest symptom of MSDs. | | Y – but depends on medication | Y | Y | Y – joint and muscle pains are symptoms of ME/CFS | Y - includes Medically unexplained physical symptoms (MUPS) | Y – migraine Y - MS Y – Parkinson's rigidity and muscle spasms, dystonia, cramps | Y - common side-effect due to physical causes but 10-15% have central post-stroke pain due to brain perception | Y – headaches common | Y – up to 50% of patients with a cancer diagnosis experience pain |
| Fatigue | Y – overwhelming, chronic fatigue that comes with MSD | Y | Y – but depends on medication | Y | Y | Y – major problem for people with ME; fluctuating/varying amount of energy/stamina | Y | Y – epilepsy postictal Y- MS Y – migraine: fatigue & tiredness are features of the pro and postdrome stages of migraine attacks Y – Parkinson's related to both symptoms but also lack of sleep at night and daytime sleepiness | Y - very common problem. 25% experience extreme long-term fatigue | Y - Extremely common. frequently limits ability to work full time | Y affects 75-100% of people with cancer; some have persistent symptoms 5-10 years after treatment |
| Depression (also disability-related) | Y- Often co-morbidities: MSD and depression | Y – prevalent and linked to a lack of confidence | Y – on discovery that CVD is a life time condition. Depends on medication. | Y | Y | Y | Y | Y – Parkinson's, MS, migraine, & epilepsy | Y - approximately 30% experience post-stroke depression | Y - very common as TBI related to loss of previous job and relationships | Y – 25% of people with cancer develop major depression |
| Stress and anxiety | Y – Stress and anxiety | Y – if stress | Y | Y | Y | Y – and stress itself | Y - common and key | Y – Migraine: panic | Y - fear of | Y | Y |

Annex C: Factors that affect ability to work, for people with long-term health conditions (part of the Health and Work Service Workshop report)

| | | | | | | | | | | | |
|---|---|--|-------------------------------|---|-----------------------------------|----------------|--|--|--|--|---|
| | can bring on a flare in inflammatory conditions such as Rheumatoid Arthritis (RA) often requiring emergency care and time off work. Can affect working hours (see below). | isn't addressed then it can cause mental health problems | | | | can trigger ME | barrier to work | attacks Y – epilepsy Y- Parkinson's: in particular, anxiety and stress makes Parkinson's worse. | having another stroke in particular | | |
| Cognitive Difficulties (also disability-related) | | Y – concentration and focus can be affected | Y – but depends on medication | Y | | Y | Y | Y – Parkinson's, MS, migraine, & epilepsy Memory a particular issue for people with epilepsy | Y - wide ranging and common. Inc memory, planning, decision-making, 30% will have aphasia – affects speaking, understanding, reading and writing | Y - very common and prevents people being able to work | Y – during treatment and post treatment |
| Incontinence (also disability related) | | | | | Y – caused by persistent coughing | | | Y – MS and Parkinson's Y – epilepsy during some types of seizure | Y - 20% experience long tem incontinence | | Y – pelvic radiotherapy can lead to long term bowel and bladder dysfunction in up to 50% patients |
| Loss of Confidence | Y- due to joint deformity self esteem and confidence affected. People can develop fear for future livelihood and prospects. | Y | | Y | Y | Y | Y – common for people with chronic pain Y – MS Y - epilepsy. Often related to depression/low self esteem. People with epilepsy often avoid social situations Y- Parkinson's: social | Y – migraine: loss of confidence is common particularly when people feel their abilities are called into question due to their condition. Y - MS Y - epilepsy. Often related to depression/low self esteem. People with epilepsy often avoid social situations Y- Parkinson's: social | Y - common effect often due to cognitive difficulties especially aphasia | Y - frequent mistakes causes reduced confidence | Y |

Annex C: Factors that affect ability to work, for people with long-term health conditions (part of the Health and Work Service Workshop report)

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| | | | | | | | | embarrassment due to tremor, being accused of being drunk, fear of “freezing” when out or trips, falls, stumbles – lots of other issues too eg. saliva control, speech problems, continence that lead to people feeling more isolated. | | | |
| Other symptoms or side effects of condition/treatment | Y – Rheumatoid Arthritis can also affect the lungs, heart, & eyes. | Y – drug side effects can cause drowsiness and weight gain (this can affect confidence) | | | Y – problems related to steroids (skin and bone problems) and difficulty with lifting as this incapacitates the auxiliary muscles that many rely on when breathing | | Y - side effects of some medication Variable Functional impairment in some cases | Y – Migraine: overuse of medication; migraine hangover period Y – “on off” fluctuations in Parkinson’s can be due to loss of effectiveness of medication or condition itself. Also, there can be speech problems: people may have a quiet voice or speech may be slurred. | Y - Hemianopia, hemiplegia, visual impairment, hearing loss. | Y - Epilepsy, behavioural problems | Y- dependent on cancer type and treatment |
| Disease trajectory/severity | Y – fluctuating condition and unpredictable ¹ | Y – fluctuating condition and unpredictable | Y – fluctuating and complex condition Many people with CVD have co-morbidities | Y – fluctuating condition. Progressive illness (rapidly and slowly depending on type of diabetes) | Y – this is a major issue as most people go many years being told they have asthma or a heart condition when in fact they have a lung condition | Y – fluctuating condition | Y - Fluctuating but can be extremely long term | Y – Parkinson’s and MS are progressive conditions and affect people in different ways. Y – severity of migraine can change/link to age. Y – there are 40 different types of epilepsy, it is an individual and variable condition. | Y – sudden onset. Every stroke is different with wide range of potential affects. Largest cause of complex adult disability. | Y – sudden onset. Once survive the initial injury – expect to live normal life span | Y – fluctuating condition and unpredictability. Significant differences in outcomes for different types. |

¹ Most LTCs are fluctuating conditions, which have changing needs. These changing needs must be taken into account when looking at their ability to work. Some conditions occur after a long period of good health, whereas others occur alongside other conditions and poor health.

Annex C: Factors that affect ability to work, for people with long-term health conditions (part of the Health and Work Service Workshop report)

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| Delay in diagnosis/misdiagnosis | Y - RA and Ankylosing Spondylitis can be very difficult to diagnose and a lot of damage can occur due to delay in referral to specialists. Can delay the decision to stay in or return to work. | Y – people can get misdiagnosed or can receive changes in diagnosis. This in turn might result in changes of medication which can affect people | | | | Y – diagnosis can be a problem as symptoms similar to other conditions | Y – difficulty in diagnosis/misdiagnosis of cause resulting in people not being appropriately treated, medicated or able to self manage ² | Y – Parkinson’s and MS: delay in diagnosis/difficulties in accurately diagnosing Y – epilepsy: diagnosis can often take years. There are high rates of misdiagnosis of epilepsy when patients have a condition called psychogenic non epileptic seizures | | People with TBI may not initially appreciate the full impact of their cognitive problems | Y |
| Management of condition | Y - Self management education to help people with arthritis is not widely available due to budget restraints. Limited help available if GP not aware of patient support groups. | Y – conditions can fluctuate even when it is being managed | | Y – some people with diabetes may not be looking after their condition | Y – some people are not taught about exercise for self management. Access to pulmonary rehabilitation depends on where you live and whether the service is available. Many patients are also not shown the correct use of their inhalers resulting in them not receiving a full dose of their medication. | | Y - self management can be supported by access to review/appropriate support | Y- MS: Due to relapses MS can be complex and difficult to manage. Relapses can happen suddenly and can result in a new set of needs developing. Y – Parkinson’s is fluctuating and unpredictable – medication has to be on time and this can be difficult at work. Someone with Parkinson’s may be on 30 tablets a day or more. | Y - depends on stroke. Emotional and psychological impact not well understood, not often diagnosed and not well supported | Y - due to not realising full impact of condition, many return to work too soon unsuccessfully | |
| Increased risk of developing other conditions | Y - People with RA have an increased risk of COPD and heart related issues. Also people with MSDs have increased risk of obesity due to joint pain and lack of activity/exercise. | Y – medication can cause diabetes and heart conditions and neuromuscular problems | Y - heart disease is connected to so many other LTCs | Y – risk of developing stroke | | | | Y – Parkinson’s leads to increased risk of dementia. | Y- risk of cardiac events and further stroke. Vascular dementia (caused by stroke) is second most common form of dementia. | Y - epilepsy | Y – risk of developing secondary cancers, lymphedema, CVD. |
| Co-morbidities | Y – significant overlap | Y – significant | Y | Y | Y | Y | Y | Y – Parkinson’s, MS, | Y – diabetes, | | Y |

² Around half of those with chronic pain who have been seen by the Fit for Work Team (Leicester FFW service) Jobcentre Plus pilot were not appropriately diagnosed/treated on entry. This points to an issue around clinical expertise and understanding of chronic pain.

Annex C: Factors that affect ability to work, for people with long-term health conditions (part of the Health and Work Service Workshop report)

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| | with mental health | overlap with MSDs. Overlap with other physical conditions e.g. if someone is diagnosed with diabetes then they may develop mental health problems. While medication for mental health problems can cause diabetes | | | | | | migraine & epilepsy. Epilepsy is linked to learning disability, mental health and dementia. | high blood pressure, epilepsy | | |
| Flare Ups | Y – need for immediate treatment but poor GP access | Y – people may require sectioning | | | Y – some patients have rescue packs (steroids and antibiotics) to use when they can't get to a GP (weekends etc) but not all GPs will give them out | | Y | Y- MS people can have sudden relapses Y – not so much flare ups but if someone with Parkinson's has overdone it they may be exhausted or have problems next couple of days. | | | |
| Time out of work for medical appointments³ | Y | Y | Y | Y | Y – including for a pulmonary rehabilitation course | | Y | Y-MS: If a person with MS takes Tysabri this involves a monthly infusion Y – Parkinson's | Y | | Y |
| Disability-related factors | | | | | | | | | | | |
| Reduced Mobility/loss of motor skills⁴ | Y- Walking even short distances can be very problematic as can sitting or being in the same position for a period of time Also, loss of grip and strength in muscles due to reduced levels of physical activity due to joint pain and | Y – some anti-psychotic drugs can result in people experiencing Parkinson-like symptoms e.g. tremors and loss of dexterity | Y – but depends on medication | Y – High risk of amputation. Immediate foot care required on a regular basis. Can lead to unplanned absences from work. | Y - big issue, particularly for people with Chronic Obstructive Pulmonary Disease (COPD) . People have difficulty walking/bending/stretching (often due to fatigue, low energy levels, breathlessness) | Y – eg lack of balance | Y | Y – one of the symptoms of Parkinson's is freezing (sudden inability to move) Embarrassment due to loss of motor skills/functions Y- MS | Y - Most common are upper and lower limb difficulties including spasticity, visual impairment, balance problem. | Y - sometimes | Y |

³ This has an impact on colleagues' workloads and relationships with colleagues. In turn this can cause the employee to lose confidence/suffer depression.

⁴ Reduced mobility can prevent/make it difficult for people to get to work (eg getting on/off public transport) and prevents/makes difficult daily task/activities – impacts on daily living.

Annex C: Factors that affect ability to work, for people with long-term health conditions (part of the Health and Work Service Workshop report)

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| | (unfounded) worries that exercise will worsen MSK cond. | | | | | | | | | | |
| Agility, including loss of fine motor skills eg dexterity⁵, posture & coordination | Y - AS in particular has a devastating effect on posture due to curvature of the spine | Y – some anti-psychotic drugs can result in people experiencing Parkinson-like symptoms e.g. tremors and loss of dexterity | | | Y – linked to type of work a person is doing | | Y - can be an issue | Y – Parkinson’s and MS eg loss of balance can cause falls Y – Parkinson’s: Slowness of movement or poverty of movement in Parkinson’s | Y | Y -occasionally | |
| Sight loss | Y - rare but in some severe cases of RA | Y – some drugs cause visual problems | | Y – sight loss is progressive due to chronic nature of the condition | | | | Y – people with MS can develop optic neuritis (partial or complete loss of vision). They can lose/regain sight. | Y – 20% have long term visual problems | Y –hemiopia or blurred vision common | |
| Renal failure | | | | Y – renal failure is progressive due to chronic nature of the condition | | | | | | | |
| Sensory factors | | Y – if someone is experiencing psychosis then they may experience hallucinations. Deafness may be a long-term side effect of antipsychotics | | | | Y – heat and light sensitive ⁶ ;some people with ME can’t work at a computer screen | | Y- MS: a symptom of MS can be numbness in hands/limbs. Temperature sensitivity both hot and cold can affect someone with MS. For example high temperatures can cause symptoms to flare up. Y – Parkinson’s can cause some problems with vision | Y | Yes – loss of smell and taste | |

⁵ Fine motor skills enable functions such as writing and grasping objects.

⁶ Linked to workplace issues. Eg, a change in the temperature in the workplace can affect people with ME/CFS who can have problems with temperature control.

Annex C: Factors that affect ability to work, for people with long-term health conditions (part of the Health and Work Service Workshop report)

| Environmental factors | | | | | | | | | | | |
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| Employer beliefs/ attitudes/behaviours (including awareness of Equality Act)⁷ | Y - difficult for employer and colleagues to have empathy for a 'hidden' condition that fluctuates | Y – employer discrimination is a huge concern | Y - Much depends on ability of manager to manage individual with LTC | Y | Y | Y | Y | Y – Migraine: also linked to stigma of the condition ⁸ Y - Parkinson's and MS: employers may not want to employ due to progressive nature of the illness Y-MS hidden symptoms and the fluctuating nature of the condition may cause employers to think their employee is fine or lead them to believe that they do not suffer from MS. Y – Epilepsy: There are lots of misunderstandings about epilepsy and what to do if individual has a seizure. See below. | Y – that stroke causes physical disabilities. There are many hidden effects and some fluctuating effects of stroke that can be equally as debilitating | Y – not many people understand the 'hidden disability' resulting from TBI | Y - line managers have a very emotional reaction to cancer which can lead to a lack of communication & affects ability to manage individual well. Lack of understanding and fear can be a factor. |
| Stigma | Y – stigma. Employer may think a MSD is less serious than it is. Stigma may also be have a negative affect on promotion prospects. | Y – huge stigma makes disclosure unlikely, in turn makes it difficult for employers to manage | | | Y – there is a lot of blame around lung disease because people associate it with smoking (even though not all lung disease is caused by smoking – eg not everyone with COPD has smoked). This can lead to a lack of sympathy for and understanding of the condition. | Y – significant problem; issues with employers not believing employee suffers from ME/CFS | Y – there may be issues around understanding of the condition, its impact and belief the individual has the condition | Y - Epilepsy is a very stigmatised condition and as a result many people do not disclose (leads to safety issues in work place). Y-MS: as some people have hidden symptoms other people may believe they don't have MS. | Y –stroke survivors report that people think they are stupid or incapable due to cognitive disabilities or aphasia | Y – hidden disability, colleagues lack understanding | Y |
| Work environment (generally) | Y - physical barriers can prevent remaining in or returning to work | Y | Y | Y | Y – some changes to the work environment could make it harder to return to work | Y – some changes could make it harder to return to work | Y - may need workplace adjustments | Y – Parkinson's, MS, migraine, epilepsy Y – MS: new | Y – aids and adaptations needed to address | Y | Y |

⁷ Relationship with line manager is key – a bad relationship with a line manager can be exacerbated by a long-term/chronic condition.

⁸ For example, employer may believe that employee is 'faking' a migraine.

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| | | | | | | | | symptoms could result in the need for changes to environment, such as a chair to sit on if you work in a shop and are not able to stand all day. | physical disabilities caused by stroke | | |
| Type of work and organisation/demands of the job⁹ | Y | Y | Y | Y | Y | Y | Y - may need workplace adjustments | Y – Parkinson’s, MS, migraine, epilepsy Y – Parkinson’s can be unpredictable and also reduces people’s ability to “multitask”. This puts added stress on the person as most jobs involve reliability and time and task criteria | Y - physical disabilities, weakness in upper and lower limbs and fatigue can make physically demanding work difficult. Flexible and phased returns to work can help | Y | Y |
| Working hours¹⁰ | Y – need flexibility in working hours (start and end times). It can often become difficult to maintain hours previously worked. | Y – may require flexibility in working hours | Y | Y | Y – need flexibility in working hours | Y – need flexibility in working hours | Y – need flexibility in working hours | Y – Parkinson’s, MS, migraine, epilepsy. Epilepsy: fatigue can be seizure trigger for some types of epilepsy which means flexible working is needed. People who have night seizures may not be able to work in the morning as they recover. | Y – fatigue | Y – need phased re-entry and negotiate breaks and may not manage to return to full time work | Y - need flexibility in working hours; and phased return to work more successful. |
| Workplace interpersonal relationships | Y - due to the lack of awareness of RA and other inflammatory arthritic conditions, work colleagues can be insensitive and not understand the day to day variations of the condition | Y | Y | Y | Y | Y | Y - can be issues around understanding of the condition and implications the condition has at work | Y | Y – can affect the ability to understand situations and makes it difficult to judge how to act appropriately. Aphasia affects the | Y | Y Lack of knowledge, fear and stigma can be issues |

⁹ This includes whether the job is physically demanding, whether the employee works on their own or as part of a team, and size of the organisation/team (long-term sickness absence in small teams/organisations can be particularly problematic). These issues needs to be looked at in conjunction with an understanding of the condition (symptoms/side effects) eg someone who becomes sensitive to light and temperature might not be compatible with certain types of work. People with LTCs can be sensitive to changes in the work environment/changes to the type of work.

¹⁰ A phased return to work was generally felt to be helpful, however participants questioned whether people with LTCs would be able to afford not to go back to work full-time.

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| | | | | | | | | | ability to communicate and understand | | |
| Perceived workplace support | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y |
| Workplace layout/setup¹¹ and whether adaptations made to facilitate RTW | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y | Y |
| Travel to work¹² | Y - access to Blue Badges is getting more difficult due to changes in legislation ¹³ | Y | Y | Y | Y | Y | Y | Y – Parkinson’s, MS, migraine, epilepsy Many people with epilepsy are barred from driving. | Y | Y | Y |
| Attitudes/behaviours of healthcare professionals (HCPs) | Y – GPs pay more attention to some conditions and are ‘rewarded’ for caring for some conditions (not MSDs). There are few Incentives for GPs to diagnose/treat MSDs. | Y - HCPs often have low expectations of people with MH problems have which may de-motivate them to RTW ¹⁴ . | Y | Y | Y | Y | Y – also a lack of clinical understanding and expertise on chronic pain | Y | Y | Y | Y - Majority of GPs have not received any education or training about the long-term effects of cancer & its treatment. Awareness in secondary care is higher but they don’t feel confident to discuss potential consequences of treatment. |
| Social impact of LTCs¹⁵ | Y - MSDs have a massive impact on relationships and family life. | Y | Y - particularly important as some CVDs are hereditary ¹⁶ | Y | Y | Y | Y | Y | Y | Y - particularly important as predominantly young males | Y |
| Other environmental factors | Y - smoking increases the risk of RA considerably and if continuing to smoke the treatments are less effective. | | | | Y - impact of pollution and cold/humidity on respiratory function | | | | Y - Family beliefs and attitudes | Y – compensation | |

¹¹ Includes ergonomics/equipment design for the workplace, workstation, work equipment.

¹² Can be associated with fatigue.

¹³ The Blue Badge scheme allows disabled drivers and passengers to park nearer to where they're going. The Government has recently changed the process for assessing who should get a Blue Badge in line with the wider reform of disability benefits.

¹⁴ This is a particular issue for people with schizophrenia. Linked to loss of confidence.

¹⁵ LTCs can cause social isolation and makes people more vulnerable.

¹⁶ With hereditary conditions, employees may also be caring for a family member with that condition. This can cause added pressure which in turn can lead to depression etc. This issue applies to other hereditary LTCs.

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| Socio-economic deprivation | Y | Y | Y | Y | Y | Y | Y | Y | Y | y | Y |
| Personal factors | | | | | | | | | | | |
| Age | Y - RA and AS and PsA tends to strike in the prime of life unlike OA which tends to be age related. Children from birth to 16 with JIA. | Y – the onset of severe mental health problems usually occurs in early adulthood | | Y - T2 diabetes tends to be 40+ | Y – COPD usually affects people over 35 (although most not diagnosed until their 50s) | | Y – number s with chronic pain likely to increase due to increase in older workforce | Y – Parkinson’s: late 50s/early 60s Y – Migraine: severity/frequency may change with age Y- MS average age of diagnosis is between 20-30s | Y - 25% of strokes in UK happen to people under the age of 65. Younger people more likely to return to work. However, many older strokes need to continue to support family. | Yes – tends to affect young men with their working lives ahead of them | Y some higher in older people |
| Gender | Y - RA 3:1 ratio women to men and AS slightly more young men than women | | | | | | | | Y - men more likely to return to work than women | Y - more men | Y |
| Poor understanding of own condition | Y - can lead to inappropriate interventions/support | Y – people can lack insight into their own condition | | | | | Y – also poor understanding from HCPs | | Y – lack of insight. Every stroke is different therefore every stroke survivors need for support is different. This will be a challenge for employers. | Y – lack of insight | |
| Personal beliefs/attitudes | Y | Y | Y | Y | Y | Y | Y can be key to self management | Y - all | Y | Y | Y |
| Family’s beliefs/attitudes | Y | Y | Y | Y | Y | Y | Y | Y - all | Y – particularly fear of triggering another stroke | Y | Y |
| Financial issues | Y | Y | Y | Y | Y | Y | Y | Y - all | Y | Y | Y |
| Disclosure | Y- disclosure unlikely. Many with RA don't wish to disclose because they will be treated differently (due to stigma of condition) and disclosure can impact on career progression/result in | Y – disclosure unlikely (see stigma section above) | | | | Y – difficulties with disclosure due to stigma | Y – difficult | Y - epilepsy due to stigma Y-MS: people with MS may be afraid to disclose for fear of losing their job or fear that people will not understand how their MS impacts on | Y- depending on the effects but emotional impact (due to brain changes) and pshycological impact are often difficult to disclose | Y – often shame associated with cause of TBI (e.g. assault, suicide attempt) | Y – difficulties with disclosure due to stigma |

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| | reduced career prospects. | | | | | | | them as a result of hidden symptoms. | | | |
| Other personal factors¹⁷ | Y | Y | Y | Y | Y | Y | Y | Y - all | Y – sudden onset but the condition can improve over time. | Y | Y - Workability improves over time (usually at least up to 18 months) for a range of common cancers, irrespective of age, but remains lower than in other comparison groups |

¹⁷ This includes life satisfaction, relationships, caring responsibilities, debt, education, physical exercise during leisure time, lifestyle choices, personal support including confidence building and human interventions.