Improving Lives: The Work, health and Disability Green Paper

Consultation response from LUPUS UK, February 2017

1. INTRODUCTION

LUPUS UK is the registered national charity that supports and represents people affected by systemic lupus erythematosus (SLE), discoid lupus erythematosus (DLE), as well as other forms of lupus and those approaching a diagnosis.

The most frequently observed form of lupus, systemic lupus erythematosus (SLE) is an uncommon, complex illness of the immune system, a condition in which the body's defence mechanism begins to attack itself through an excess of antibodies in the blood stream, causing inflammation and damage in the joints, muscles and other organs. 90% of lupus patients are female although men and children can also be affected.

Lupus can affect any part of the body and can cause many different symptoms, often mimicking other diseases such as rheumatoid arthritis or multiple sclerosis. The disease may be triggered by various means (exposure to UV light, certain viruses and changes in hormones, for example) and can present in a bewildering number of ways. Some of the more common symptoms of lupus can include; joint/muscle pains, rashes, kidney problems, extreme fatigue, heart and lung involvement, increased risk of miscarriage, hair loss, depression, flu-like symptoms, seizures, and headaches/migraines. With its many symptoms, lupus can often be overlooked by a GP or consultant which frequently delays final diagnosis and a vital start to necessary treatment that may contain the disease and limit any potential damage. It currently takes an average of seven and a half years from the onset of symptoms for somebody to get a diagnosis of lupus in the UK.[i]

There is no cure for lupus. Those diagnosed usually receive ongoing treatment to lessen the impact of the many symptoms but there are always side effects. Lupus can adversely affect the lives of those with the disease and their families, and it often influences the person's mental wellbeing and their ability to work. Approximately 25% of people with lupus have to retire early on medical grounds.[ii]

In this response to the Green Paper, we offer support for many of the health proposals, and our comments will help in developing and refining the government's approach to the important issues that it seeks to address. We welcome and endorse the recognition in the Green Paper of the need to address health conditions and work.

<u>Key Points</u>:

- People with lupus need timely access to person-centred, joined-up diagnosis, intervention, rehabilitation and treatment.
- Employers need information and support to enable them to make adjustments to assist people with lupus to work.
- Those people with lupus who may be capable of some work may require flexible, individualised support in their return to the workplace, which is joined-up with their healthcare providers.
- Those people with lupus who have been declared by their healthcare team as being unable to ever return to work, with no scope for improvement should be **exempt** from reassessments for disability benefits.
- Further engagement with LUPUS UK with detailed support from the lupus community is needed to realise the opportunities that the Green Paper proposes.

2. APPROACHES AND COMMITMENTS OUTLINED IN GREEN PAPER TO TACKLING MUSCULOSKELETAL CONDITIONS AND WORK

We endorse the recognition given to musculoskeletal conditions (which include lupus) in the Green Paper as a very significant issue for work; as musculoskeletal conditions are the biggest cause of disability and pain in the UK, with less than two-thirds of working age people with a musculoskeletal condition in work. To support change for people with lupus, LUPUS UK strongly supports the following approaches and commitments outlined in the Green Paper:

CARE PLANNING: (para 249). LUPUS UK strongly agrees that it is 'unacceptable' that 'only 12% of people with musculoskeletal conditions had a care plan … when we know that earlier diagnosis and treatment of musculoskeletal conditions would, in many cases, prevent further deterioration in the condition and enable the individual to stay in work.'

PROVIDING MUSCULOSKELETAL CARE IN LOCAL AREAS: (para 250) [Government is] 'supportive of new ways of providing musculoskeletal care, which are being developed in a number of local areas. These include physiotherapists working from general practice surgeries and self-referral to musculoskeletal services'.

DEVELOPMENT OF CARE PATHWAYS: As stated in (para 253), LUPUS UK supports this approach: [Government wishes] 'to trial new kinds of approach for musculoskeletal services so that people's health and employment needs are met in the best possible way, including the further development of community based pathways and developing better links between treatment and employment support'.

MUSCULOSKELETAL DATA: LUPUS UK agrees as stated in (para 254) 'There is also a lack of detailed information about what kinds of musculoskeletal services are currently commissioned, and the extent to which the services meet local need. The government will therefore work with NHS England to identify opportunities for regular collection of data about incidence, prevalence, clinical activity and outcomes of musculoskeletal patients and services in England'.

2.1. NEXT STEPS

LUPUS UK believes that it is vital that these commitments outlined in the paper are ratified with action in these areas.

LUPUS UK looks forward to working with the DWP and NHS to provide more detailed support in the next stages of the programme.

3. RESPONSES TO QUESTIONS IN THE GREEN PAPER:

LUPUS UK has focussed its response to the Green Paper on the questions where we feel we can add most value. In addition, there are a number of general points.

3.1. GENERAL POINTS

There is a two-way interface between difficulties with lupus and work. Exacerbation of lupus symptoms or the development of additional musculoskeletal problems may occur if certain risks in the working environment are not recognised and catered for. Additionally, lupus itself can limit a person's ability to work.

PREVENTION

As identified in the Green Paper [para 33], prevention is important. It will be important to have a range of interventions across the health and care systems to try and prevent the worsening of health conditions to the extent that they are disabling and to avoid the development of preventable long-term health conditions.

In brief, LUPUS UK believes that for effective prevention, the following is required:

- **At every age people should be supported to maintain and improve the health of their joints, bones and muscles. Information, education and physical activity are important in enabling people to live well with a long-term health condition.**

- **For many long-term health conditions, including lupus, earlier diagnosis, treatment and early intervention is paramount as this can prevent further, needless disability, reduce pain intensity and improve quality of life.**

- **People living with long-term health conditions should receive high quality information and individualised advice about diet and healthy eating by a qualified professional. Maintaining a healthy balanced diet which supplements for any discovered deficiencies is crucial in enabling people to live well with a chronic health problem.**

- **To effectively avoid preventable long-term health conditions, it is essential for there to be a workforce – including medical, clinical, sport and leisure professionals (e.g. life-guards, fitness instructors) and others - trained in musculoskeletal conditions, together with well-informed, supported patients.**

For more detailed information about prevention, ARMA (The Arthritis and Musculoskeletal Alliance) will be publishing a policy position paper in early 2017 on primary and secondary prevention of musculoskeletal conditions.

3.2. RESPONSES TO QUESTIONS

Question 2.2: What specialist tools or support should we provide to work coaches to help them work with disabled people and people with health conditions?

Training and knowledge for work coaches in the various health conditions that they will encounter will support their ability to provide a person-centred approach.

There is often co-existence of mental health conditions with lupus, for example it can often be associated with anxiety and depression, thus work coaches must be well prepared so that they can take a whole-person approach.

As there are over 200 musculoskeletal conditions, access and linking work coaches to those with expertise and knowledge in these conditions, such as appropriate research and patient charities, clinical experts and groups would also be of benefit.

Question 3.1: What support should we offer to help those ‘in work’ stay in work and progress?

Legislation could be introduced requiring employers to utilise existing services (such as the Access to Work scheme) to help support their workers with long-term health conditions such as lupus.

Funding to the Access to Work scheme should be increased greater than real terms, allowing for additional service provision and further support to enable employers much more flexibility when hiring people with disabilities or health conditions. This could allow individuals with a restricted capacity to work or those with relapsing and remitting health conditions to reap the health and social rewards of employment, whilst not risking their health by being pushed beyond their capability.

Disability benefits and financial support are key to helping people with disabilities and/or health conditions maintain employment and live independent lives. In-work disability benefits must be protected from any further reductions or restrictions to the eligibility criteria.

Changes should be made to ensure people with lupus can rely on sufficient financial support, making it easier for them to move in and out or work and vary their hours as their condition requires.

Question 6.1: Should the assessment for the financial support an individual receives from the system be separate from the discussion a claimant has about employment or health support?

The assessment of the ability to work would best take place in the healthcare system, rather than the Department for Work and Pensions, as this setting will help to lessen concern and anxiety around removal of benefits.

Question 7.2: Building on our plans to exempt people with the most severe health conditions and disabilities from reassessment, how can we further improve the process for assessing the financial support for this group?

The assessment of the ability to work would best take place in the healthcare system by medical professionals who have a suitable understanding of the conditions they will see and the potential effects of work upon an individual. Current assessors cannot possibly have a sufficient understanding of the wide range of medical conditions that affect the individuals they are required to assess. This limits their ability to perform a fair and reasonable assessment and can result in people with specific needs being put at risk of harm.

Those people with lupus who have been declared by their healthcare team as being unable to ever return to work, with no scope for improvement should be exempt from reassessments for disability benefits.

Work is not always an appropriate outcome for everyone. People with complex conditions who are unlikely to be able to return to work should be supported to reach self-defined goals.

Consideration of those with health conditions that are exacerbated by stress needs to be made when planning the reassessments of people claiming financial support. At present the stress of being called for a reassessment (largely due to the high numbers of people having their award taken away unless the decision is successfully appealed by the claimant) is having potentially severe consequences for the health of claimants with certain conditions such as lupus.

Question 8.2: What expectation should there be on employers to recruit or retain disabled people and people with health conditions?

Employers should:

- Audit the health needs of their staff.
- Make reasonable adjustments to support employees with health conditions, like lupus.
- Develop a plan to promote good health of all their employees.
- Provide training for line managers about the health conditions of their employees and their individual needs.
- Understand the potential effects and limitations of any health conditions that their employees have so that, together with the employee, adjustments can be made to improve outcomes for everybody.

Employers should incorporate flexibility into the working environment for people with a long-term health condition like lupus, for example, working from home where appropriate and recognising that their condition may fluctuate.

Employers should also ensure people get access to occupational health provision which incorporates musculoskeletal health expertise.

Question 8.3: Which measures would best support employers to recruit and retain the talent of disabled people and people with health conditions?

The **Access to Work** scheme should be supported by a greater than real terms increase in funding. The Department of Work and Pensions should undertake immediate and ongoing promotion of Access to Work to target people with long-term health conditions.

Question 8.3(e): What role can information campaigns play to highlight good practices and what they should cover?

Information campaigns to employers should direct them to patient advocacy groups and charities that offer high quality information about their respective health condition(s) and can demonstrate good practices.

It is also important that information campaigns to employers should include musculoskeletal health. A good example is the musculoskeletal toolkit that is being developed by ARMA with key stakeholders in the employer community.

In addition, the legal obligations for employers should also be incorporated, including equality and accident prevention.

Question 9.1: How can existing government support be reformed to better support the recruitment and retention of disabled people and people with health conditions?

Funding to the Access to Work scheme should be increased greater than real terms, allowing for additional service provision and further support to enable employers much more flexibility when hiring people with disabilities or health conditions. This could allow individuals with a restricted capacity to work or those with relapsing and remitting health conditions to reap the health and social rewards of employment, whilst not risking their health by being pushed beyond their capability.

Question 11.3: Are doctors best placed to provide work and health information, make a judgement on fitness for work and provide sickness certification?

LUPUS UK strongly supports the proposal in the Green Paper to extend the issuing of fit notes to other professionals including physiotherapists and podiatrists. Allowing other healthcare professionals such as physiotherapists to issue fit notes would save both patients’ and doctors’ time and ease the strain on general practice. It would enable patients to be assessed and advised by the appropriate professional at an earlier stage allowing them to begin their rehabilitation more quickly.

Question 11.4: Turning to the fit note certificate itself, what information should be captured to best help the individual, work coaches and employers better support a return to work or job retention?

The Fit note should include ‘Working with reasonable adjustments’, and say what support is available to employers to enable this. It should also provide information about relevant patient advocacy groups and charities that can provide additional information and support for individuals, work coaches and employers.

Question 12.1: How should access to services, assessment, treatment and employment support change for people with mental health or musculoskeletal conditions so that their health and employment needs are met in the best possible way?

EARLY INTERVENTION

Early-intervention is an approach which offers a real opportunity to limit the potential accumulation of damage caused by lupus, to allow it to be managed promptly and effectively, restoring function, so people can avoid work loss. While the policy of early intervention is widely accepted, there are barriers that exist to early intervention delivery in practice. Understanding these barriers and developing mechanisms to overcome these can enable change. There are a number of levers for overcoming the barriers to early intervention including the points outlined further below:

- People suspected of having lupus should have early access to an integrated and multidisciplinary medical team who are trained in inflammatory autoimmune conditions and equipped to identify, treat and/or refer so that it can be managed promptly; preventing potential damage accumulation and supporting the person's ability to work.

- **High-quality care pathways** and patient journeys (see below);

- **For employers**, a positive culture needs to be developed so that conversations regarding health can take place freely and help find solutions. This means tackling the stigma related to adjustments an employee may need and improving the general understanding related to health problems throughout the workforce.

PATIENT JOURNEYS AND CARE PATHWAYS

- Current **care pathways** are reactive, acting when a problem arises. However, what is required to improve support for people with lupus is a more proactive, preventative care pathway. A **care pathway** is needed that supports a high quality, person-centred, preventative, timely and joined-up, seamless journey across the whole healthcare system, making optimum use of the skills of the multi-disciplinary and medical team, enabling people to self-manage their conditions where possible; and increase awareness of what can be achieved. A good care pathway is underpinned by good communication throughout and sharing of information across teams and care settings.

- Within the care pathway, it's important for people to get the service they need, including timely access to surgery - where required – to support return to work.

- One in five visits to the GP is for a musculoskeletal condition. Remodelling of the patient journey in primary care has been shown to be effective, for example, self-referral to services such as physiotherapy allows patients to access services directly without having to see their GP or anyone else first. Patients can either refer themselves directly into existing physiotherapy services or see a physiotherapist based in general practice. Self-referral to services such as physiotherapy is 25% cheaper to the NHS than a GP referral and has been fully evaluated and recommended by NICE. General practice physiotherapy roles are a new form of self-referral which further develops GP and physio services, enhances patient care and reduces the GP workload. Patients with MSK symptoms can opt to see them instead of the GP to assess, diagnose, advise and provide exercises and, when needed, carry out

further investigations and refer on. This puts physiotherapy expertise at the start of the patient's journey; at the place they are most likely to seek help first.

REHABILITATION AND RETURN TO WORK

- **Rehabilitation and return to work** enables an employee to return to the workplace as soon as possible and fulfil their potential despite any on-going problem**.**

- Too often people receive intensive rehabilitation in hospital and just after discharge they often have long waits when they get home, if it's available at all. While patients wait, their recovery is halted and can reverse – causing lasting disability, distress and deterioration of health. Half of all people who suffer a hip fracture are left with a permanent disability and can no longer live independently. To maximise independence and reduce disability, rehabilitation needs to continue from hospital to home, be easy to refer back in to and be rooted in the community.

- ***For employers*** rehabilitation and return to work means talking to employees openly so that the workplace and work requirements can be adjusted and adapted to the physical limitations of the worker. Employers also need to extend flexibility to their employees to allow for fluctuation in condition(s).

DATA

- High quality data on lupus is essential to guide service provision. Data areas include assessing the needs of the local population, activity of local health services and outcomes delivered by health care.

- An analysis of Joint Strategic Needs Assessments - which provide an overview of the health and wellbeing needs of the local population – by Arthritis Research UK's report *A Fair Assessment* shows that only about a third consider musculoskeletal conditions. With musculoskeletal conditions as the leading cause of disability and pain in the UK, a good starting point to understanding the needs of the local population is to incorporate a mandatory section on musculoskeletal conditions and work, and include timeframes for data collection.

- Currently, the tools used to measure musculoskeletal outcomes tend to vary between different healthcare settings and conditions; as such, there is a pressing need for a unified system of measuring outcomes that can be applied throughout the care process for patients with different musculoskeletal conditions. Developed by Arthritis Research UK's Primary Care Centre at Keele University in collaboration with the University of Oxford and in partnership with people with arthritis, the **MSK-Healthcare Questionnaire**[iii] is a short questionnaire that allows people with conditions such as arthritis or back pain to report their symptoms and quality of life in a standardised manner and it includes a question around work. Over time, such information could be used to understand and improve the quality of services provided to people with arthritis.

Question 12.2: How can we help individuals to easily find information about the mental health and musculoskeletal services they can access?

Patient advocacy groups and charities produce a significant number of resources to support people with various health conditions including mental health and musculoskeletal conditions. These resources are generally available in a range of formats including booklets, videos, online information and helplines. An example of information produced by LUPUS UK for employers and employees can be found at http://www.lupusuk.org.uk/working-with-lupus/

The primary care setting should 'prescribe' accredited patient support groups at diagnosis as these patient support groups have some excellent resources to aid employers and employees. One simple method of identifying organisations that produce sufficiently high-quality information is to utilise the Information Standard accreditation scheme which is managed by NHS England.

REFERENCES

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[i] LUPUS UK Member Survey 2009
[ii] LUPUS UK Member Survey 2009
[iii] See http://www.arthritisresearchuk.org/policy-and-public-affairs/policy-priorities-and-projects/musculosketal-health-services/musculoskeletal-health-questionnaire.aspx