2017 General Election

Manifesto

NLRP12 is a unique, non-profit organisation based in Edinburgh advocating for, and supporting, patients suffering from the ultra-rare familial cold autoinflammatory syndrome type 2, other rare autoinflammatory diseases and rare diseases in general. We work together with our global partners to improve the lives of the people living with a rare disease, and their families, around the world. By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, we aim to strengthen the patient voice and shapes research, policies and patient services. More information is available at http://www.nlrp12.com.

One in seventeen people in the UK are affected by rare diseases at some time in their lives. Because they are fragmented over 6,700 specific rare diseases, the community's voice goes virtually unheard in in today's political landscape.

Rare diseases are disabling, often chronic, progressive, degenerative and life-threatening. 75% of rare diseases affect children and 30% of rare disease patients die before the age of 5. They are often highly complex and sometimes generate very specific care needs. These factors combined with lack of treatment create huge obstacles to the provision of holistic care and generate significant burden for patients and their families and carers. This is aggravated by the current economic situation the NHS and Social Care: patients/carers are often not able to find an adapted job/occupation and provide for themselves, increasing families' financial burden. However, due to the therapeutic/healthcare advances, people with rare disease now have longer life expectancy in certain circumstances, higher functioning and greater expectations towards an autonomous fulfilling life.

The need to provide social services and support adapted to rare diseases is recognised in the European Commission Expert Group on Rare Diseases Recommendations to Support the incorporation of rare diseases into social services and policies, directed to the European Union Member States and the European Commission.

1. In line with these recommendations, general election candidates from all parties must ensure that they are prepared to be at the forefront to integrate the challenges of people with rare diseases and their carers into employment and social policies by promoting:

- Adapted, flexible and non-discriminatory employment and adequate social services to allow people with chronic/complex diseases and carers to actively contribute to society; the high poverty rate of people with disabilities can be reduced as their employment rate increases;
- Adapted, non-discriminatory schooling for children with rare diseases and complex conditions;
- Adaptation of the government's functions, including disability assessment systems to consider disabilities, incurring not only from the impairments but also from socially disabling situations like complex care pathways;

- Accessible goods, services and built environment.

People with rare diseases and their carers often have complex and specific needs, they require NHS and Social Care policies to modernise and adapt to the current EU legal and policy framework and allow for parents of children with rare disease specific needs and those with dependent relatives to better balance caring and professional responsibilities.

NLRP12 believes the parliament must cover the concerns of populations with specific needs like rare disease patients. It is the responsibility of the Government to step up implementation, and make full use of opportunities such as EU funds and sharing of best practices. EU funds can be used to support the uptake of social measures that answer the needs of people with complex and progressive conditions before we leave the European Union.

Provisions must be made so that people with complex needs will never be deprived of their much-needed social support when entering the labour market.

2. Government can take the lead and should look at providing (and encouraging with their vendors to provide) secure labour contracts for people with rare diseases or their carers. These can provide the opportunity to enter and remain in the labour market if the position and workplace are fully adapted to their evolving needs (working from home, allowing time for medical appointments, areas dedicated to rest, upscaling of competencies).

People with rare diseases and their carers are willing to join the labour market and some have the capacity to do so if supportive accommodation and access to the workplace are facilitated correctly. It is important to evaluate the added value of these people's contribution to the economy and not just focus on the cost of the social support they receive.

Technological change has a huge potential to support people living with chronic complex and debilitating conditions such as most rare diseases and to manage their health conditions and care pathway. To achieve this, new technologies must be designed to adapt to the specific needs of users. Users should therefore be involved in the development of new accessible and affordable technologies right from the beginning.

Government should legislate for provision for rare disease patients with complex needs, and their families, services that will span the full life cycle, from childcare, education and training to entry and retention into the labour market, as well as smooth job transitions to delay exit from the labour market.

3. Besides ensuring accessibility to goods, services and assistive devices for people with disabilities, government should also legislate for improving the assessment of disability and the accessibility of sports, leisure, cultural/recreational activities, goods and quality community-based person-centred services.

4. Government should promote and practice the convergence of health and social systems to support the development of holistic and integrated care pathways and erase the disparities between constituencies and areas to eradicate the current postcode lottery.

5. Rare diseases are often complex, progressive, disabling and many of them affect children. Access to mainstream education for children with severe disabilities/complex care needs is difficult and sometimes segregated.

Obstacles in the education system can strongly affect future employment prospects and lead to social exclusion. Legislators must remember that children and adults with rare diseases and

disabling conditions have a right to education and life-long learning (as per the UN Convention on Right of Persons with Disabilities), that most often their physical health does not affect their intellectual functions, that education and training allow them to fully participate in society and in the economy.

Therefore, people with rare diseases must be fully integrated into the mainstream education system where possible and requested. Specific adjustments must be made to allow for full inclusion and equal opportunities: physical access to the classroom, adaptation of the teaching methods, materials, evaluation process and support to teachers in the classroom for severe cases. To be prepared to deal with complex needs, the teachers' curriculum should raise awareness about the specific educational and sanitary needs of some pupils. An educational care protocol should be promoted.

The education system must also be flexible enough to provide for necessary obligations such as attending regular health appointments or administration of treatments. The teachers, educators and fellow students should be made aware of the specific medical and ambulatory needs of people with rare diseases and be prepared to embrace and deal with the differences. Families of pupils with rare diseases are more than willing to participate in awareness and educational activities and promote non-discrimination, respect for differences and equal opportunities.

Additionally, education measures must go beyond school and include skills enhancement and life-long learning to allow people with complex conditions to enter and remain in the labour market for if possible.

6. Mainstream social services often respond inadequately to the expectations and needs of people with rare and complex diseases, especially when the demands are specific to the disease or to the complexity of the care pathway. This inadequacy of the social services is more severe for people with rare diseases who may have a low income.

Patients and their families are known through the medical world as experts with their disease and most are willing to share their needs and experiences to support the design and implementation of services and benefits together with the drafting of social policies (employment, social services, planning, etc.) that are adapted and respond to those needs. Patient involvement in decision making regarding the development and implementation of services and policies must therefore be a requirement.

Additionally, patients' and their family's contribution must be supported financially, as is the case of the contribution of the other experts informing decisions.

Patient organisations' role in informing decisions and creating informative and educational materials for the general public (raising awareness, reducing stigma and improving the social integration of patients) must also be recognised and supported.

At workplace level, trade unions should either have a patient representative among them or a patient contact to guide their work.

7. The care of people with complex conditions such as rare disease should not be restricted to (para)medical aspects but consider social inclusion and educational development. Persons with rare diseases often need care support from different categories of health professionals, social workers and social services. These multidisciplinary needs require coordination of health, social and community services.

Integrated care can address the gaps in the coordination between medical, social and support services and must be developed to promote the autonomy and the quality of life of people with complex diseases and their carers. This includes the recognition of the diagnosis and its consequences on the daily life of patients and their carers: recognition of the degree of disability/dependency and access to corresponding resources (school, social services, employment and housing provisions).

Innovative holistic and integrated care pathways will need to link up health services with the social and support services that people with rare diseases and their families use daily (e.g. school, transport, leisure and social services) and ensure the transfer of information and expertise between service providers.

The setting up of one-stop-shop services (e.g. Resource Centres for Rare Diseases) and/or of case management services that centralise the coordination of care can relieve the burden of care management for patients and families and can also be financially neutral.

The various ongoing reforms of integrated care across Europe must guide the need to support people with complex conditions and disabilities, and not just focus on hospital-based models which evolve around less complex and common chronic diseases.

National plans for rare diseases, now being developed and implemented in most European Union countries and all countries within the United Kingdom, need to guide and structure integrated care for rare diseases within the framework of our national and local health and social system (including job entry, work place accommodation and job retention).

8. People living with rare diseases frequently need long-term care. Although physical or intellectual impairments require long-term care, other less physically and mentally disabling health conditions also require long-term and holistic care pathways to overcome the complexity of the disease and support patients' autonomy and carers' support.

Government should promote measures that empower patients in decision making and support patients/families affected by rare diseases to participate in decisions regarding their care plan and their life project (develop information and training tools for patients and families to empower them and increase their capacity to undertake a participative role in care provision; care providers to give non-directive assistance and support patients and families to express their wishes, set priorities, take decisions and direct their own services if they wish to do so).

Government should also promote coordination and networking between all parties involved in the care provision of persons affected by rare diseases, including public, private and civil society organisations as well as between providers and patient/disability organisations.

Socioeconomic research in the field of rare disease care provision and organisation should be supported both at national and supranational level to better understand:

- The socio-economic burden of rare diseases;
- The accessibility and appropriateness of healthcare services, including social services for people living with a rare disease and their families;
- The effectiveness and cost-effectiveness of social services and support, as well as rehabilitation and assistive technologies for people with a rare disease;
- Innovative care practices in health and social services and their impact on the quality of life of people living with rare diseases.

Integrated Care, may provide cost-effective solutions that deserves to be explored and adopted throughout the United Kingdom.

9. Government must have a long-term vision encompassing childcare, education, training and entry into the labour market for children with rare diseases. These children must have equal opportunities right from birth that will help them be better integrated in society.

Children must be integrated into mainstream school and adaptations to their specific needs must be implemented if possible before attendance starts.

Carers of children with specific needs need support: childminding to allow respite, childcare facilities with opening hours that match the parents working hours, and properly trained staff. This will enable parents who are working or studying to keep their position open and secure financial sustainability of the family. Adequate coordination between the health, social and education services is key to support such schemes.

10. Housing adaptation is the main investment made by patients and families affected by rare diseases (Federación Española de Enfermedades Raras' study on the Situation of Social-sanitary needs of PLWRD, 2009).

Housing adaptation is necessary to support people with complex health conditions and disabilities. This allows for independent living and autonomy.

Provisions for 'Adapted Housing Services' must be made as they make it possible for a person living with a rare disease to live as independently as possible, while being monitored by supportive staff to help with any daily routine activities that cannot be performed independently.

People with rare diseases can thus enjoy a high level of independence and autonomy, while being integrated into a community of peers without jeopardising their safety or their clinical and therapeutic needs.

On average, 16% of people with rare diseases (up to 24% for the low-income group) are forced to move house because of their disease. Governemnt should also consider Adapted Housing in the form of a specific local/regional grants awarded to the patient's family to cover any house adaptation work, prevent families from moving into other facilities or adjust regular buildings to certain specific needs.

Making all new public buildings accessible to people with complex needs right from the beginning to avoid expensive modifications afterwards must be promoted.

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