

## **Towards A Labour Carer's Manifesto**

### **The Labour Carers Group**

#### **Caring and its Impact**

Carers are individuals or families looking after a person with a disability or a special need, or families looking after an elderly relative. To qualify for Carer's Allowance the carer must provide regular and substantial care, for at least 35 hours a week.

The act of caring has implications for the whole family. Many carers have given up their careers to undertake caring, and many siblings have given up educational, training and employment opportunities to help the family out with care overall.

The pressure that carers are under is immense, with implications for relationships, finances and the mental and physical health not of the carers themselves but for their whole family, including siblings. Their lives have been transformed by the act of caring for someone else. They have often had to make massive adjustments to their lives.

However, many carers feel they are under-valued by society. They feel excluded from the discourse about hard working families, hard-working people, even though they work extremely hard over long hours. For long periods of time, often for many days and weeks at a time, carers are either caring or have to make themselves available to care with little or no respite.

With little financial support available, many carers struggle financially and often their families face poverty and hardship. Carer's Allowance is the lowest benefit and does not provide a gateway to other benefits.

#### **Change has to come.**

A number of carers, who are Labour Party members and supporters, have come together in meetings, hosted by John McDonnell MP, to form a network to discuss the issues carers face and to start the process of dialogue as the first step in creating a Labour Carers' Manifesto.

To promote this dialogue and to take the first steps down the path of developing a Carers' Manifesto we have identified the first three policy priorities we wish the Labour Party to discuss and address.

#### **Carers Allowance**

We believe that Carer's Allowance should not be seen as a benefit but as a salary, as carers work incredibly hard for their allowance. A large number of pensioners and students are not eligible for Carer's Allowance even though they continue to provide care. Carers should be paid a decent wage that they can live on, at least at the level

of the real living wage, regardless of their age. They provide a valuable service that would be considerably more costly to the public purse if the state had to step in and provide this care.

### **Support as of Right and Ending Means Testing**

Many carers feel they are in a constant battle to secure the support they need for the person they care for. They consider the whole assessment process to be extremely stressful and humiliating for the person they care for. In addition, means testing is incredibly invasive to the point that many carers have declined any help and only in extremis and often on the point of collapse will they apply again. A major source of stress is caused by having to comply with very tight and rigid, inflexible regulations. Carers consider it's time to introduce greater flexibility in the interpretation of regulations governing access to support and to consider ending means testing altogether.

### **Improved training for health and local authority administrative staff.**

Carers frequently feel patronised and unsupported by the health and local authority bodies they have to deal with. The staff of these organisations are under pressure and carers have too often found that they are not fully trained to understand the Care Act.

Consequently, carers too frequently receive partial and sometimes misinformation, which deters them from pursuing and securing the support to which they are entitled.

There is a need to review and improve the staffing resources and staff training of these bodies.

### **Access to professional support, legal advice and advocacy.**

As well as the day to day domestic duties of caring, carers find themselves having to undertake legal, financial medical, educational, administrative and recreational tasks. Carers feel it is near-impossible for individuals without adequate professional support, advice and advocacy to stand up against authorities, who often act ineffectively and, on occasion they believe, unlawfully.

This is considered especially true when parents seek to address their major worry of what happens to their loved one when they pass away or are unable to provide some of the vital support their adult children need. This is an extremely frightening prospect for carers. It is also of concern to them that when their child becomes an adult and they no longer have legal rights to make decisions for their child, their views are then not sufficiently taken into account by the local authority.

An unpaid carer's voice appears to them to be seen as very low on the list of 'credible sources'. They are told that they might be 'over-emotional', 'too involved',

and have 'unrealistic expectations. In turn this level of patronising treatment adds to the stress and worry of carers. Legal help is far out of reach for most.

That's why the provision of ready access to professional support, legal advice and advocacy services is seen as essential. A specific Carers Ombudsman could go some way towards providing the accountability that is needed.

### **Extending Respite Care and Befriending Schemes**

The stress that carers can be under, and the mental health implications not only for themselves as individuals but for their whole family can sometimes appear to be insurmountable. The low level of benefits for the disabled do not provide a quality of life, for example enough for a holiday every year, or other recreational activities or in any way enough to save for these opportunities.

Whilst some are fortunate enough to have access to respite care, care facilities can't always cope with the complex needs of the cared for person. Carers who don't have access to respite arrangements in place are unable to undertake activities that most people would take for granted, for example the opportunity to go to the dentist, have a night out or a weekend away with their partners. They just don't have the finances to afford or the support staff to permit such things.

The provision of a befriender, who could facilitate social activities with the cared for person that include, for example, playing a game, going to the park, visiting restaurants, going to football matches or cinema, would also take a lot of pressure off the carer. They could also help with personal problems that the cared for person may not wish to discuss with their family.

### **The cost of living crisis has hit Carers hard.**

The cost of living crisis has exacerbated many of the financial worries carers already face.

For example, parents who care for children at home with medically complex issues often rely on a large amount of medical equipment that requires mains power or charging. This can increase the family's energy bills threefold. There is no way that the family can cope with these costs without putting the child at risk.

Similarly, households who use more energy and water than average due to increased use of laundry and washing due to a medical condition are incurring additional charges.

With the continuing rise in the cost of food, specialist diets for the cared for person are becoming unaffordable.

The WaterSure scheme has been introduced to cap the cost of water within an area. Introducing a scheme to cap Food and Energy costs would relieve the stress and worry for families and make sure that the child's health is not put at risk.

## **Tell Us What You Think and Join us.**

These are five initial areas we have identified to enable us to kick off the discussion about developing a Carers' Manifesto.

Our aim is to stimulate a thorough discussion within the Labour Party about the reality of being a Carer in our country today and about the policies Labour needs to tackle the challenges carers face.

We want to bring carers who are Labour Party members or supporters together to promote a clear agenda for reform that Labour can campaign for and introduce when it comes to power at the next election.

So, tell us what you think is needed.

Better still, join our Labour Carers' Group.