

**Do you agree with our proposal that the new offence should cover all formal health and adult social care settings, both in the private and public sectors? Please explain your views.**

Yes  No

Comments

Parkinson's UK strongly agrees that the new offence should apply in all formal adult health and social care settings, in both the public and private sectors. In the interests of clarity, the offence should also apply in settings run by the third / voluntary sector, which employs over a quarter (27%) of the social care workforce in Scotland.<sup>1</sup>

We believe that there must be zero tolerance of wilful neglect and ill-treatment in any setting. An individual who is receiving formal care services should be entitled to the same protection from ill treatment and wilful neglect whoever is providing that care and wherever it is received. This is particularly important in the context of health and social care integration, where there is a need to align standards and regulation of care between health and social care sectors so that people have consistent rights to high quality care.

People with Parkinson's typically require very high levels of health and social care as their condition progresses, and this care is often delivered in the full range of settings including inpatient hospital care, short or long term stays in care homes and in the person's own home. Wilful neglect and ill treatment can take place in any of these settings.

Advanced Parkinson's symptoms often include a combination of physical disability, cognitive deficits and communication problems, although dementia is often under-identified in Parkinson's, and people frequently lack a diagnosis of dementia. People with Parkinson's rely on complex medication regimens to manage their symptoms, and if they do not take their medication at the right time and at the right dose, this can lead to uncontrolled symptoms. The complex nature of Parkinson's can mean that people are particularly vulnerable to substandard care, neglect and abuse, and may be less able to make their concerns known.

We would particularly emphasise our support for the principle that the legislation will cover formal care provided within people's own homes, where people who receive care may be particularly isolated. We are aware that the issue of regulation of personal assistants employed by disabled people is a complex one, but Parkinson's UK believes that as personal assistants are paid for their role, they should be subject to this offence.

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<sup>1</sup> SSSC (2014) Scottish social services sector: report on 2013 workforce data Online at <http://data.sssc.uk.com/data-publications/22-workforce-data-report/90-scottish-social-services-sector-report-on-2013-workforce-data>

**Do you agree with our proposal that the offence should not cover informal arrangements, for example, one family member caring for another?**

Yes  No

Comments

Parkinson's UK agrees that informal health and social care arrangements should not come under this legislation.

We believe that it is more appropriate for concerns about care delivered by unpaid carers to be addressed via existing safeguarding procedures. We also note that coercive or neglectful behaviour can sometimes arise from a lack of support for the carer to help them deal with the situation they find themselves in, so there is a need to prioritise funding and support for carers to prevent situations like these from arising.

We believe that there is also a risk that including informal arrangements within the legislation could have the unintended consequence of discouraging family members, friends or neighbours from assisting someone with Parkinson's for fear of being prosecuted for "getting things wrong".

**Should the new offence cover social care services for children, and if so which services should it cover? Please list any children's services that you think should be excluded from the scope the offence and explain your view.**

Yes  No

Comments

Parkinson's UK has no comment to make because we do not work with children.

**Should the offence apply to people who are providing care or treatment on a voluntary basis on behalf of a voluntary organisation?**

Yes  No

Comments

On balance, Parkinson's UK supports the principle that volunteers who are providing care or treatment on behalf of a voluntary organisation should be included in the scope of this legislation. We believe that voluntary organisations that seek to provide formal care or treatment using volunteers must support and train their volunteers to ensure that they provide high quality care and treatment. It would be unfortunate if voluntary sector organisations were deterred from offering care and treatment services provided by volunteers, but we would hope that including them within the

regulation would be part of an agenda that believes that voluntary sector organisations provide high quality volunteer services. People who use formal care services provided by volunteers should have the same legal rights to protection as those whose formal care is provided by paid workers.

However, the legislation will have to include very clear definitions of what constitutes care or treatment provided on a voluntary basis, and what is meant by “on behalf of a voluntary organisation”. We believe that these definitions should make clear that the law applies to volunteers providing a formal care or treatment service – ie a service that is akin to a paid service but using volunteers rather than paid workers.

It must be clear that the offence will not apply in situations where volunteers are **not** providing a formal care or treatment service. As is the case with unpaid carers, there could be unintended consequences if this is not made clear. We believe that it could dissuade people from volunteering in non-care or treatment roles, for fear that they might be prosecuted if someone came to harm “on their watch”. It may also have the effect of encouraging risk-averse voluntary sector organisations to over-regulate their volunteers to protect them from a perceived risk of prosecution.

There may also be some crossover between volunteers and unpaid carers, where people who are volunteers in a non-care or treatment capacity also provide a level of unpaid care or support to relatives, friends or neighbours. The law needs to be able to differentiate between volunteers providing formal care and treatment, and volunteers who also act as unpaid carers.

In addition, the law must be clear that it does not cover cases where a volunteer is not providing care “on behalf of” an organisation. For example, in a small number of cases, people take on voluntary roles of which a host organisation is unaware. In these cases, we believe it would be more appropriate to address issues via normal safeguarding procedures, as in the case of unpaid carers.

**Do you agree with our proposal that the new offence should concentrate on the act of wilfully neglecting, or ill-treating an individual rather than any harm suffered as a result of that behaviour?**

Yes  No

Parkinson’s UK agrees that the new offence should focus on the conduct of the provider/practitioner, rather than any consideration of the harm caused to the victim of the offence.

There must be zero-tolerance to wilful neglect and ill-treatment in care settings, regardless of the degree of harm this action goes on to cause. Individuals subjected to the same treatment may experience very different consequences.

Some Parkinson's symptoms leave people at particular risk as a result of wilful neglect and ill treatment. Those whose movement and / or swallowing are affected can be at particular risk of malnutrition, dehydration and choking for example. People who have severe mobility issues are at particular risk from pressure sores and infections. Falls are a major risk for people with gait, movement, and balance issues, and people with incontinence need to receive regular continence care to protect their dignity and skin integrity. In addition, medications management is a particular issue for people with Parkinson's throughout the course of their condition, and the failure to support people to take their medication on time and at the correct dose could constitute wilful neglect or ill treatment.

Parkinson's UK has a well-established Get It On Time campaign, which aims to ensure that people with Parkinson's get their medication on time, every time in hospital and care homes. This is reflected in the NHS HIS Care Standards for Neurological Health Services.

The main treatment for Parkinson's is medication. Medication can help to manage symptoms but does not stop the underlying progression of the condition. If a person with Parkinson's is unable to take their prescribed medication at the right time, the balance of chemicals in their brains can become severely disrupted – leading to the symptoms of the condition becoming uncontrolled.

Uncontrolled symptoms can include:

- being unable to move, speak, eat or swallow
- uncontrolled movements
- distressing psychotic symptoms

It can take weeks to restore effective symptom control. In some cases, the person never recovers to the same level they were before their medication was missed or administered late.

A 2013 YouGov survey completed by 4,777 people with Parkinson's, family members or carers of a person with the condition in the UK, found that of those having been in hospital or a care home, 30 per cent reported not having received their medication on time.<sup>2</sup>

Every person with Parkinson's who does not receive their medication on time will be affected differently. Some are never able to fully recover their health, while some face few long-term complications as a result. If the offence proposed in this consultation was only to cover the extent of the harm caused as a result of ill-treatment or wilful neglect, the absurd situation where the same action, by the same person, in the same institution may result in the prosecution in some cases and not others would clearly arise.

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<sup>2</sup> Parkinson's UK and YouGov, *Survey of people with Parkinson's and their friends, family and carers*, 2013

**Do you agree with our proposal that the offence should apply to organisations as well as individuals?**

Yes  No

Comments

Parkinson's UK supports the idea that the offence should apply to organisations as well as individuals. This is appropriate where the culture, practices and policies of an organisation can be seen to contribute to an individual's acts of ill treatment and neglect or have failed to act to protect service users.

As inquiries into the Mid-Staffordshire and Winterborne View scandals have shown, the culture and management of organisations has a major role to play in preventing individuals from acting in a way that puts people who use services at risk. In these cases, organisations should be held responsible.

**How, and in what circumstances, do you think the offence should apply to organisations?**

Yes  No

Comments

Parkinson's UK believes that in cases where the organisations culture, practices and policies have contributed to the ill treatment and neglect of people who use services, the organisation should be covered by the offence. There should also be the option of prosecuting managers if there is a strong case that they enabled or failed to act to prevent individual workers from wilfully neglecting or ill-treating people who use services.

**Do you agree that the penalties for this offence should be the same as those for the offences in section 315 of the Mental Health (Care and Treatment) (Scotland) Act 2003 and section 83 of the Adults with Incapacity (Scotland) Act 2000?**

Yes  No

Comments

Yes. Parkinson's UK believes that the principle of parity between the offences under these pieces of legislation is an important one.

However, we also note that the maximum term of imprisonment under this legislation is two years, while in England the maximum term is more than twice as long, at five years.

Parkinson's UK believes that, in light of the seriousness of these offences,

there is a strong case for setting the maximum sentence on conviction at five years, and amending the other two Acts to bring all three pieces of legislation into line.

**Should the courts have any additional penalty options in respect of organisations? If so, please provide details of any other penalty options that you think would be appropriate.**

Yes  No

Comments

Parkinson's UK welcomes the potential for additional types of penalties to be issued in respect of organisations.

In addition to fines, Parkinson's UK would support removing the organisation's leaders and banning them from holding leadership roles in the future. There should also be the option of issuing a public reprimand of the organisation.

We are interested in how the regulatory powers held by NHS HIS, the Care Inspectorate (and health professional bodies or the Scottish Social Services Council for individuals) will interface with this legislation. While these processes – and any sanctions – would be separate, we would expect that the regulator(s) would become involved with any organisation where there was an issue of wilful neglect or ill-treatment.

**What issues or opportunities do the proposed changes raise for people with protected characteristics (age; disability; gender reassignment; race; religion or belief; sex; pregnancy and maternity; and sexual orientation) and what action could be taken to mitigate the impact of any negative issues?**

Comments

No comment.