



The all-party parliamentary group
Ageing and older people

Inquiry into human rights and older people:

Protecting our rights as we age

Spring 2018

Our inquiry

The All-Party Parliamentary Group (APPG) was established to engage with the political and legislative issues affecting people in later life.

As part of our work in the 2017-2022 Parliament we decided to pursue an in-depth inquiry into human rights and older people, with the aim to:

- Understand the human rights challenges facing older people in the UK and internationally, including the adequacy of current human rights standards for protecting their rights
- Produce recommendations for how older people's human rights could be better protected

We held meetings between October 2017 and April 2018, hearing from a range of expert speakers on key topics. The inquiry has also accepted written evidence during this period and is grateful to the organisations and individuals who submitted their views.

This report outlines the key themes to emerge from our inquiry and focuses on recommendations the APPG wishes to make as a result of its discussions and written evidence we received.

One of the recurring points was how older people are seen by both themselves and others. Our conclusion from this is that older people should be seen as individuals, not as a homogeneous group, and that human rights are important for them no matter where they live. Human rights should be used to ensure that people of any age are treated with dignity and respect and they must also protect us from the additional challenges that can face us as we get older.

There have been some excellent achievements over the last twenty years and the inquiry heard how human rights standards can provide vital protection for older people by helping to change practice and procedure, culture and attitudes, and offer redress when breaches of human rights have taken place. Legislation like the Human Rights Act and the Equality Act, for example, have enhanced the rights and lives of older people in the UK and research from the British Institute of Human Rights has found that local enforcement of these standards is making a genuine and real difference to individuals' lives.

However, from the APPG's meetings and the written evidence we received, we are concerned that too many older people around the world, including the UK, continue to face unacceptable limits to the protection of their rights, extensive discrimination and overt abuse in their daily lives. This not only robs them of their dignity but also their ability to live independently and autonomously. It became evident through our inquiry that these gaps are numerous and significant in their impact.

Despite progress, the problem remains that there are particular issues relating to older people and ageism that are not being addressed adequately by existing policy and legal frameworks. At an international level, current human rights agreements do not cover age discrimination, few treaties explicitly mention older people and, although momentum is building towards an international convention for the rights of older people, one does not yet exist.

We hope the recommendations in this report will form a basis from which we can work to improve the rights of older people and better define the protections we can provide as we age.

Recommendations

1. A new international convention

The UK government should support the creation of an international convention on the rights of older people whilst preserving and enhancing these rights through domestic legislation.

2. Combatting ageism and discrimination

The UK government should ensure older people are able to participate in their communities, to use key services without discrimination and be treated with equality, dignity and respect.

3. The right to health and care

A person's right to health and care does not diminish with age, and older people must be cared for with dignity.

4. Communication and engagement

The development and communication of rights should be improved, with better awareness among older people, their families and service providers, and more inclusion of older people's own views.

5. Local ageing strategies prioritising rights

Local authorities should include rights within ageing strategies specific to their area and use human rights to drive improvements through collaborative local leadership.

Recommendation 1: A new international convention

The UK government should actively support an international convention on the rights of older people.

Existing international conventions do not adequately protect the human rights of older people and the APPG supports the development of a new international convention that would address gaps and improve protections of these vital rights. The convention should be developed in the same way as conventions promoting protection of the rights of children (UNCRC) and discrimination on the grounds of race (UNCERD).

A new convention would transform debates about how to respond to global ageing by clearly articulating how human rights apply to people in later life and reaffirming a person's dignity and respect, regardless of their age.

It should have a strong emphasis on recognising older people as rights holders, promoting and protecting their right to dignity, autonomy, and the right to actively contribute to society, as well as the rights to care, better health and the right to protection from age discrimination.

A fuller articulation of these rights within a formal convention would allow older people in all parts of the world to claim them more effectively by placing legal obligations on individual states. These obligations would bolster civil society and improve accountability by providing older people with an important tool for holding their governments to account.

The process of developing, agreeing and implementing a convention would, in itself, be beneficial by driving the rights of older people and their needs up the agendas of governments worldwide. This process would be an important awareness-raising tool, bringing attention to the issues facing older people across the world, the way they are treated, and to the systemic ageism that runs through our society and would provide focus for decision makers to mainstream these rights into all policies and legislation.

The APPG urges the UK Government to use its global influence to drive forward this hugely significant and positive step in strengthening human rights globally.

Alongside international efforts, complementary steps should be taken in domestic legislation.

There remains significant uncertainty around what leaving the EU will mean for the rights of older people (both British citizens living in mainland Europe and European citizens living in the UK) and in particular the rights within the Charter of Fundamental Rights of the European Union that are currently not in UK domestic law.

The UK government should clarify its position on these as soon as possible and at the same time could explore new domestic legislation that explicitly states and improves upon the rights of older people.

New legislation could be a chance to strengthen older people's rights, by including areas such as the right to food. It could also include an obligation for government departments to consider how their legislation affects older people and could include a government duty to take steps to reduce harmful stereotypes.

The introduction of a Commission for the Rights of Older People across the four nations of the UK, as Wales has already done, would provide oversight to ensure that rights are pro-actively pursued and upheld.

The APPG recommends that the Government take immediate action in these areas and if international progress towards an overarching convention is slow, should consider whether it would be beneficial to take quicker steps domestically.

Recommendation 2: Combatting ageism and discrimination

The UK government should ensure older people are able to participate in their communities, to use key services without discrimination and be treated with equality, dignity and respect.

No one should lose out or be treated unfairly because of their age, yet the APPG is concerned that older people face persistent ageism and discrimination in a range of areas, including health and care, employment, and consumer services.

This has the unacceptable consequence that older people frequently experience discriminatory treatment that can dramatically affect their wellbeing, confidence, job prospects, financial situation and quality of life.

The APPG is also concerned at the way that older people are represented in the media, which can have a wider impact on the public's attitudes to older people and on how older people perceive themselves.

We are worried that older people's rights are also affected in other areas of daily living.

For example, inaccessible housing, lack of public transport and access to basic services such as public toilets can inhibit older people's independence and ability to participate in their communities. This can be exacerbated by health conditions and can be particularly difficult for older people with dementia, where something like poor signage can increase the risk of becoming lost and anxious. This can undermine an older person's confidence and they may avoid going out, leading to self-neglect and isolation.

Everybody should be able to live in an age-friendly environment that enables them to lead independent and fulfilling lives and so we would like to see local planning, regeneration and street management teams made aware of the implications of demographic change and the views of older residents when designing and maintaining neighbourhoods. This should include maintaining pavements and footpaths, reducing road obstacles and providing benches to help people keep active as they age. The system must enable older people to be able to advocate for themselves.

Nationally, the Department for Business, Energy & Industrial Strategy's consumer markets green paper is a chance to make significant progress on this and we hope it will be a chance to improve the experience of older consumers and to ensure they are able to access the services they rely on. The Government should ensure that there is no reduction in consumer protection as a result of reductions in public spending.

More widely, we would also like to see a stronger obligation to eliminate harmful ageist social norms and practices, including by raising awareness of the rights and capacities of older people, countering ageist perceptions and practices, and eliminating any harmful practices that adversely affect their dignity or personal security. There should also be more assistance to older people when making claims and accessing justice. This could be done by providing more information on remedies and how to access them, alongside better provision of legal support and aid.

What is ageism?

Age discrimination can be legal under certain circumstances and the Equality Act allows for age discrimination when it can be 'objectively justified'.

That means the employer or service provider must show that they have a good reason for discriminating on the basis of age.

However, some examples of illegal ageism include:

- losing a job because of your age
- being refused interest-free credit, a new credit card, car insurance or travel insurance because of your age
- receiving a lower quality of service in a shop or restaurant because of the organisation's attitude to older people
- being refused membership to a club or trade association because of your age

Recommendation 3: The right to health and care

A person's right to health and care does not diminish with age and older people must be cared for with dignity.

The Human Rights Act includes the right to life but it also includes other Articles relevant to care, like dignity and neglect, involving people in their own care and avoiding belittling treatment and stigma. Despite this, when poor care occurs the first response isn't necessarily to see it as a human rights issue.

During our inquiry we were pleased to hear how human rights can be a useful way of looking at these problems and improving access to healthcare. We heard how human rights approaches can be empowering to older people and their families, help to get things moving by using legal duties and how they can reduce confrontations in situations by providing a level, standard playing field. We also heard how human rights can help to find the delicate balance of risks against rights, for example by supporting someone with dementia to be cared for at home whilst still preserving the rights that matter to them.

We make recommendations in three main areas of concern: Social care, access to treatment and palliative care.

Too many older people are going without the social care they desperately need

Funding for older people's social care in the UK is under severe pressure and this poses a real threat to older people's ability to uphold their independence and autonomy. According to Age UK, over a million older people are living with unmet social care needs and this can include help with basic daily living, like getting out of bed, going to the toilet, washing and getting dressed. For those older people who are receiving on-going care support, their experience of services is too often poor, with insufficient regard to compassion, dignity, respect and autonomy.

We are concerned that this is a result of the substantial barriers to good care that continue to exist and in some cases very poor practice.

First, funding pressure is creating staff shortages and a lack of resources, leading to poor care as staff struggle to meet individuals' needs. This can have a significant effect on the carer, as well as older people, and they risk losing their connection to the values that drew them to this profession in the first place.

Second, this is compounded by a lack of professional education and training. This can not only lead to breaches of an individual's rights but can also restrict their confidence and ability in responding to concerns.

Good human rights can change the culture within organisations and ongoing training in key areas can improve confidence and reconnect staff to their values. More practitioners should be trained in the Human Rights Act and communication skills also shouldn't be overlooked, along with the systems that facilitate proper communication between professionals and enable them to make better decisions.

Case study: Training and abuse

Abuse of older people is appalling when it occurs. Perpetrators of abuse or neglect are often people who are trusted and relied on by an older person, such as family members or care staff.

One of the cases highlighted in the British Institute of Human Rights (BIHR) advocacy project was Elsie, an elderly woman living in a care home.

She told her advocate that she was being forced to go to go places she didn't want to and he noticed bruises on her arms.

As a result of his training, the advocate recognised this contravened Article 3 of the Human Rights Act and raised it with his manager, social services, the Care Quality Commission and the police.

A system of professional registration of care staff would provide additional protection to older people.

Finally, the APPG shares the concerns of others that self-funders in care homes are lacking the rights of other residents: an older person whose residential care is funded by their council is covered by the Human Rights Act, while their self-funding neighbour living alongside them is not. This gap removes a necessary layer of protection, is a gross injustice and should be addressed as a priority. Care should be provided in a setting which the older person has chosen.

The Government must acknowledge that problems with the social care system are not only clinical but can create fundamental challenges to an older person's experience of their intrinsic dignity and wellbeing.

The shared values between care and rights (such as promoting equality and ensuring dignity) means that making progress on both is mutually beneficial and should be used for promoting the case for improvement.

It is important that the Department for Health and Social Care's green paper on social care is now delivered by the summer as promised and it should be bold enough to address the fundamental problems with the care system that create breaches of older people's rights. Alongside this there remains a pressing need for additional funding to cope with demand until a more sustainable solution can be developed and implemented.

Age should not be a factor in the treating of health conditions

The APPG is concerned about evidence suggesting older people have poorer access to treatments for acute conditions. For example, treatment rates drop disproportionately for people over 70-75 years trying to access surgery, chemotherapy and talking therapies for mental health conditions. Separately, research by Drink Wise, Age Well has also found older adults being discriminated against over referrals to treatment for alcohol problems and that they are less likely to be asked about their alcohol consumption.

Some specific conditions add further complexity to these issues. The impairments caused by dementia, for example, fall within the definition of disability within the Equality Act, yet Alzheimer's Society report challenges in getting this recognised and qualifying for needed extra support. As a result, people with dementia can frequently experience discrimination on multiple grounds.

In many developing countries too, health services remain strongly orientated towards tackling infectious disease and mother and child health, missing the health challenges faced

Good care?

Research by the European Network of National Human Rights Institutions has found deficient care across Europe, with human rights concerns in all six countries studied by the project (Belgium, Croatia, Germany, Hungary, Lithuania and Romania). This included breaches like the use of chemical restraint, residents being moved down corridors while undressed, and cases where heating had been turned off in order to save the care provider money. The project also found a lack of general knowledge about rights and obligations and a lack of clarity around the quality of care older people should receive.

Despite the overall findings, it did however identify some characteristics of good care.

Sufficient funding, staffing and training were all identified as important. In addition, the research identified beneficial small steps providers can take, like clear complaints and redress processes, residents being able to personalise their own space, adequate physical environments and older people being able to participate in tasks like cooking their own food. Spiritual and religious wellbeing is also an important consideration for many older people that should not be forgotten during their care.

Individual considerations really do matter, particularly when additional complexities exist around a person's care. The care of older prisoners is an example of this added complexity and the Prisons and Probation Ombudsman has raised particular concerns around the availability of prison facilities providing specialist care.

'Good care' is therefore not just about meeting demand but about meeting it in a way that treats an older person as the valued individual they are and good practice can therefore emerge from a person-centred approach that listens to what older people themselves actually want from their care.

by the increasing numbers of older people. There is a chronic lack of attention to and understanding of older people's health issues, economic and social wellbeing, this has severe consequences for both older people and their families. Older people who experience loneliness and/or social isolation also carry a risk of worse health outcomes.

We should change how we view dying and provide a more person-centred approach

Multimorbidity means we need to move towards a more considered and proactive approach to end of life care that sees death as a more gradual and prolonged process.

Palliative care is an area where personalised care can be particularly important and make a real difference, with good palliative care incorporating the key principles of dignity, compassion and respect.

Unfortunately, this isn't always the case and the complexity of conditions at the end of someone's life can make it harder to provide the care someone needs. Research from Manchester Metropolitan University, for example, has found that practitioners often fail to understand the specific needs around substance use and this can result in poor and negligent care at the end of someone's life, depriving them of the right to a good and dignified death.

Person-centred approaches to palliative care that allow people to make decisions on their care often results in less treatment and reduced spending in the long term, as well as a better quality of life for the person concerned. More coordination between practitioners would be beneficial to ensure someone's wishes are followed throughout their care and would bring additional smaller benefits like avoiding someone having to provide the same information to several agencies.

At a higher level, a right to palliative care situated within a UN Convention on the rights of older persons could encompass a right to choose where to die, a right to equal access to holistic palliative care without delay, including pain relief, and access to end of life care, including self-determination of how to proceed with all aspects of care planning.

Case study: Heart scan

A 60 year old man was refused a heart scan because he had a learning disability. His advocate was able to use the right to life and to be free from discrimination to reverse the decision.

Although the man sadly died before treatment could take place, this case illustrates how human rights approaches can ensure older people get the treatment they need.

Spiritual wellbeing

This is an important consideration for many older people and shouldn't be overlooked when planning their care.

MHA, a charity care provider, highlighted its Final Lap programme, which aims to ensure care homes are places where death is faced openly and with proper support. Spiritual support is an important part of this and their chaplains begin conversations with residents and relatives, creating a culture of openness where residents' last wishes can be articulated. Chaplains are also able to act as advocates where no family members are available.

Recommendation 4: Communication and engagement

The development and communication of rights should be improved, with better awareness among older people, their families and service providers, and more inclusion of older people's own views and active citizenship.

Changing culture and attitudes towards older people is an essential part of realising their rights, and a crucial part of this is ensuring people of all ages are aware of both the rights that benefit them and their obligations to others. Against a backdrop of ageist attitudes and discrimination, we should be open and honest about what human rights are, what they mean for people in later life, how human rights benefit us and explain rights in a language that people understand.

By communicating rights in a way that relate to everyday life and that connects with people in a way that is real and meaningful to them, we can make human rights rules and obligations accessible to as wide a group of people as possible.

Age UK has produced a local human rights toolkit that explains what rights older people have and how they can ensure they are enforced. This followed a project working with older volunteers across the country, listening to what they think about their rights, increasing their awareness and understanding of them and finding practical ways to work locally to improve their daily lives.

Older people should be better incorporated into discussions of their rights and the APPG would like to see more prominence given to older people's views, in particular by public sector organisations providing services and support. Serious and effective consultation is useful and should take into account the fact that older people not only have different views of their rights but also how they want to be seen in regard to them.

There is an important role for intergenerational work too in this area and older people should not be segregated. There is a real value in different generations understanding each other and this would help improve awareness of rights and how they apply to people.

Public bodies like local authorities should ensure that they create space for older people to express their preferences, and through mainstreaming the rights of older people must enable accessible active citizenship and advocacy.

Deprivation of Liberty Safeguards – Reforming and communicating a complex issue

Engagement on the reform of the Deprivation of Liberty Safeguards (DoLS) is an example of some of the challenges the APPG heard during its inquiry as it illustrates the barriers facing technical human rights issues being communicated. Due to a limited understanding of DoLS, combined with the subject being complicated, legalistic and abstract, much of the conversation has been limited to understanding what it is rather than addressing the issues facing it.

In order for reform to take place and for people to see this as an enabler of human rights, DoLS needs to be contextualised and humanised within a wider issue. By connecting DoLS to wider issues in the social care crisis and other issues around dementia and safeguarding, people can understand their role within the system and how it impacts those under it. This allows individuals to realise the personal element of an issue, which is at the heart of the impact of DoLS on older people and their families. Organisations need to rethink the way they communicate on complex rights issues, overcoming presumptions of knowledge. By providing resources that explain rights issues in a practical and accessible manner, and establishing a basic level understanding, meaningful work can be undertaken to ensure older people's rights are upheld and they understand what they are entitled to.

Recommendation 5: Local strategies prioritising rights

Local authorities should include rights within ageing strategies specific to their area and use human rights to drive improvements through collaborative local leadership.

International treaties are vital to setting the agenda and international standards but it is local and national implementation where the real differences are made. Age should not be a barrier to living well and living longer presents huge opportunities to create vibrant and resilient communities where older people can develop their interests and aspirations as integral parts of the community. Older people should have the opportunities to participate in their local area and be valued for their contribution but too many of our communities are underprepared to manage the challenges of ageing.

Local authorities can therefore have an important role in developing and implementing more effective local ageing strategies to prepare for demographic changes and make the most of the potential of an older population. Local leaders driving local decisions could dramatically improve the provision and support for older people in their area, change how authorities and agencies see and act towards older residents and transform the protection of their rights, enable advocacy and active citizenship.

Ageing strategies should, wherever possible, be based on local consultation with older people about what they want from the area in which they live. This would give the local authority a better understanding of how ageing applies to that particular area and the challenges within it. This would allow the strategy to combine improvements in rights with the broader goal of making an area more age friendly.

Age UK has produced an age friendly places guide with suggestions for how local authorities can make their communities a better place to grow older. The LGA has also developed an Equality Framework for Local Government to help local authorities, in discussion with local partners and local people, to review and improve their performance for people with characteristics protected by the Equality Act. The World Health Organisation (WHO) also provides guidance, resources and support from a network of practitioners through its WHO Global Network for Age-Friendly Cities and Communities.

Greater Manchester Ageing Hub

In March, Greater Manchester became the UK's first age-friendly city region as recognised by the World Health Organization.

The city has established the Greater Manchester Ageing Hub to coordinate a more strategic response to the opportunities and challenges of an ageing population across six key themes. This coordination includes working with partner organisations in the city, bringing together research, policy and practice together so that public services are delivered and helping commissioning decisions to be made on the best possible research and evidence.

Wales: The Older People's Commissioner for Wales

The Commissioner has statutory functions and has been active across many different areas, ranging from transport access, to public toilets and care homes. The Commissioner has the power to issue guidance that the public sector must have regard to. They can also provide advice, for example to local authorities, to fill gaps in guidance from elsewhere.

The Commissioner also has a vital public policy role. During the development of the Welsh Government's 2014 Declaration of Rights for Older People in Wales, the Commissioner used their engagement with older people in an advisory role. The declaration now acts as a proactive tool to protect rights by using the voices of older people to set out what is important to them, the rights that they have under existing legal instruments and how these rights may be being breached.

Evidence

The APPG received evidence from the following organisations and individuals:

Age International

Age UK

Alzheimer's Society

British Dietetic Association

British Geriatrics Society

British Institute of Human Rights

Drink Wise, Age Well

Equality and Human Rights Commission

European Network of National Human Rights Institutions

Greater Manchester Ageing Hub, Greater Manchester Combined Authority

Later Life Ambitions

Local Government Association

MHA

National Pensioners Convention

Older People's Commissioner for Wales

Prisons and Probation Ombudsman

Queen's Nursing Institute

Surrey County Council

Professor Geraldine Van Bueren QC, Queen Mary University of London

Mr Ian Vernon

Professor John Robert Williams, Aberystwyth University

Dr Samantha Wright and Professor Sarah Galvani, Manchester Metropolitan University