

Guiding principles

This paper sets out the set of guiding principles agreed by the Coalition of Carers to underpin and strengthen future campaigning work for carers



The story so far

From Recognition to Rights

In 2009, following some 15 years of campaigning for carer recognition, over 50 Coalition members – carers and representatives from local and national carer led organisations – met in Glasgow to take stock of their campaign so far. They acknowledged many positive achievements for carer support in Scotland, including widespread recognition of carers in government, NHS and local authority policy and the extensive national and local network of carer centres.

But this gathering of Scotland's carers movement also concluded that carers still depended largely on the 'goodwill' of statutory agencies for the provision and funding of support and noted a continuing lack of equity: the carers' movement had not yet succeeded gaining legal rights and enforceable entitlements for carers. At this meeting in 2009, the Coalition adopted a new strapline – from recognition to rights – and set out to focus future campaigning on gaining tangible rights for carers.

The Carers (Scotland) Act 2016

The joint campaign by the Coalition and Scotland's national and local carer organisations eventually led to First Minister Alex Salmond announcing at the 2013 Carers Parliament that the government had heard and understood the case for new carer legislation. The introduction of the Carers (Scotland) Bill followed in 2014. The Carers (Scotland) Act became law in 2016.

Prior to its implementation in April 2018, the Executive Committee met to take stock of the gains secured through the Act. Whilst there were some notable advances underpinned by a financial memorandum to implement the Act over five years, there were however noticeable gaps in the new legislation.

The Executive Committee concluded that, despite many years of campaigning for a shift from recognition to rights, the Act, overall, still fell short of enforceable entitlements, for example rights to regular breaks from caring, to carer advocacy or to emotional and psychotherapeutic support. The Executive Committee therefore decided that, alongside maximising the positive impact and outcomes of the Carers Act locally, the Coalition has a responsibility to continue to campaign for additional rights.

The Future Role of the Coalition

Examining the Coalition's lead role in the campaign for the Carers Act, important lessons need to be acknowledged: the Coalition has been a key player in all achievements and had acted in exemplary fashion to build broad alliances and partnerships for the advance of carers' rights. On reflection we have, at times, not advocated strongly enough for carers rights.

We need to adopt a stronger leadership role in our partnership approach with government and third sector partners. Going forward we will have clear and principled positioning for explicit carers 'rights and entitlements.

The Executive Committee recognised that the Coalition lacked a document of fundamental principles to govern and guide all campaigning work. We noted that Eurocarers was formed in 2006 with the adoption of a charter of 10 principles and that other European carer organisations have since adopted similar charters based on those of Eurocarers.

In conclusion, the Executive Committee set up a working group in 2018 to prepare proposals for a set of guiding principles, including a human rights focus, and to present these to the membership for debate, endorsement and ultimately for formal adoption.

Proposed Guiding Principles / Rights for Carers

1

Recognition and Rights

Recognition of the central role carers play in the provision of care is a human rights issue. Rights and entitlements for support in their caring role must be enshrined in statute.

2

Participation and Social Inclusion

Carers have a right to full participation in society

3

Equality

Carers have a right to equal opportunities and do not experience inequalities as a result of their caring role.

4

Choice and Co-determination

People have the right to choose freely how much care they are willing to provide. Carers are equal and active partners in decision making processes.

5

Information

Carers have enshrined rights to accessible information, advice, guidance and training.

6

Health & Wellbeing

Carers and former carers have a right to have the impact of caring on their own health and wellbeing recognised and addressed.

7

Support and Resources

Carers have a right to independent advocacy and financial, practical and emotional support in their caring role.

8

Breaks from caring

Carers must have a right to suitable regular breaks from caring.

9

Economic Wellbeing

Carers have the right not to be disadvantaged financially as a result of their caring role.

10

Employment

Carers have a right to reconcile caring with paid employment of their choice. Rights to time off and flexible working must be enshrined in statute.

Principles, Outcomes, Actions and Changes

Coalition Guiding Principles	Outcomes What success looks like for carers (personal) and for society (organisational)	Actions and Change Required How can this be achieved? Action points and changes
<p>Principle 1 Recognition and Rights</p> <p>Recognition of the central role carers play in the provision of care is a human rights issue. Rights and entitlements for support in their caring role must be enshrined in statute.</p>	<p>Carers report they are treated as equal partners and providers of care.</p> <p>Carers report that their personal outcomes are being met through a range of local supports.</p> <p>Carers are able to access support on an equitable basis in every part of Scotland.</p>	<p>Further amendment of the Carers (Scotland) Act 2016; additional rights and entitlements which reflect those of the paid workforce.</p> <p>A national and local framework of legislation, policy and eligibility provides equitable support to carers.</p> <p>The full implementation of Self-Directed Support (SDS) legislation to extend to carers.</p> <p>Carers have an active role in professional and vocational training and policy development and review.</p>
<p>Principle 2 Participation and Social Inclusion</p> <p>Recognition of the central role carers play in the provision of care is a human rights issue. Rights and entitlements for support in their caring role must be enshrined in statute.</p>	<p>Carers report a healthy work-life balance and social wellbeing.</p> <p>Carers exercise their right to participate fully in society.</p> <p>Carers feel recognised and supported within the community.</p>	<p>Further amendment of the Carers (Scotland) Act 2016; additional rights and entitlements which reflect those of the paid workforce.</p> <p>A national and local framework of legislation, policy and eligibility provides equitable support to carers.</p> <p>The full implementation of Self-Directed Support (SDS) legislation to extend to carers.</p> <p>Carers have an active role in professional and vocational training and policy development and review.</p>
<p>Principle 3 Equality</p> <p>Carers have a right to equal opportunities and do not experience inequalities as a result of their caring role.</p>	<p>Carers report being seen as multi-talented people and are accessing / exercising opportunities to lead a life of their choice.</p> <p>Carers have equal opportunities in life regardless of age, gender, ethnicity or socio-economic status.</p>	<p>Greater carers awareness within services and communities.</p>
<p>Principle 4 Choice and Co-determination</p> <p>People have the right to choose freely how much care they are willing to provide. Carers are equal and active participants in decision making processes.</p>	<p>Carers report they are aware of and exercise their choice to care</p> <p>Carers report they are confident in their ability to shape services and support, for the person requiring care and to meet their own needs</p> <p>Carers report feeling free of guilt of using a range of supports and services</p>	<p>Set out in a preamble to this that we respect the rights of people with disabilities, etc</p> <p>Self-directed support: flexibility, choice and control</p> <p>Personalised</p> <p>More access to replacement care on demand; ability to modify replacement care in a timely manner</p> <p>Additional and adequate resources are made available to carers</p>

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<p>Principle 5 Information</p> <p>Carers have enshrined rights to accessible information, advice, guidance and training.</p>	<p>Carers report being better informed about issues linked to their caring role.</p> <p>Carers are better informed about their life options outside of their caring role.</p> <p>Carers report that they are able to make informed plans and decisions.</p>	<p>Possession of necessary tools to access all required information and media channels.</p> <p>Bespoke regional and central information and guidance services.</p> <p>Signposting to comprehensive local advice, advocacy and training services.</p> <p>Mandatory carers awareness training within statutory services.</p>
<p>Principle 6 Health & Wellbeing</p> <p>Carers and former carers have a right to have the impact of caring on their own health and wellbeing recognised and addressed.</p>	<p>Carers feel supported to look after their own health and wellbeing to reduce any negative impact of their caring role on their own health and wellbeing.</p> <p>Carers report improved health and wellbeing</p> <ul style="list-style-type: none"> • early in the caring role • throughout the caring role • after the caring role. 	<p>Risk assessment of the caring role and appropriate training (including manual handling training).</p> <p>Positive health discrimination with health checks and priority care for active carers.</p> <p>Emotional support and counselling.</p> <p>After caring programmes for carers (German model).</p>
<p>Principle 7 Support and Resources</p> <p>Carers have a right to independent advocacy and financial, practical and emotional support in their caring role.</p>	<p>Carers report greater resilience and improved ability to cope with life.</p>	<p>Sufficient / adequate / full free access to appropriate formal care.</p>
<p>Principle 8 Breaks from caring</p> <p>Carers must have a right to suitable regular breaks from caring..</p>	<p>Carers report they are aware of and exercise their choice to care.</p> <p>Carers report they are confident in their ability to shape services and support, for the person requiring care and to meet their own needs.</p> <p>Carers report feeling free of guilt of using a range of supports and services.</p>	<p>Replacement care arrangements should be acceptable both to the carer and the person receiving care.</p> <p>An entitlement to short breaks (based on statutory minimum for annual leave entitlement, or childcare entitlement).</p> <p>Mix of provision, to provide for differing needs of carers.</p> <p>Right to sleep – night cover Preventative short breaks Recuperation should be guaranteed for carers.</p>

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Principle 9 Economic Wellbeing Carers have the right not to be disadvantaged financially as a result of their caring role.	Carers report improved economic wellbeing. Carers do not experience debt and poverty as a result of their caring role. Carers are supported with good financial planning.	Access to financial planning for <ul style="list-style-type: none"> • social security benefits • pension rights • housing provision • Power of Attorney and Guardianship • Wills and legal issues. Improved social security cover to avoid financial distress. Ideally, replacement of benefits with a universal basic income / living income.
Principle 10 Employment Carers have a right to reconcile caring with paid employment of their choice. Rights to time off and flexible working must be enshrined in statute.	Carers report having the choice to work and paid employment if they want to. Carers report accessing caring-compatible working hours.	Reconcile; embrace flexibility Carer Positive mandatory within statutory services



CoalitionofCarers



@CarersCoalition

The Coalition of Carers in Scotland,
PO Box 21624, Stirling FK7 1EF

T 01786 850247

E coalition@carersnet.org

www.carersnet.org



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