

What can carers' organisations offer the current debate on social care reform?

OVERVIEW

Unpaid carers were highlighted in Prime Minister Andy Burnham's 28 July speech on **reforming social care**, and Lib Dem leader Ed Davey has long said family carers must be 'front and centre' of vital changes. Both emphasise that life for millions of unpaid carers has to improve. It's 'personal' for them – both have family experience of caring – and vital for effective functioning of health and social systems and for resolving deep-seated economic issues.

My book tells the inspiring story of how carers first came to attention and came to be called 'carers', showing that:

- the world's first national carers' organisation was formed in the UK (1965);
- it rapidly gained traction as the media, public figures and ordinary citizens responded to its call for fairness for carers;
- carers' organisations have proved adept at proposing practical solutions;
- mobilising at local, national and international levels, they have shared many positive ideas about needed policy developments;
- their collaborations have produced good practices and effective policies in many countries;
- the carers' movement remains vibrant, committed and practical, working closely with governments to shape better policies.

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CONTEXT

When the NHS was founded, there was no language for carers' support; it was the 'taken-for-granted' role of women within families. Today's social care crisis, long in the making, undermines family wellbeing and NHS sustainability. Ignoring carers led to flawed assumptions about welfare states, generating persistent issues that must be fixed.

The Casey Review of Social Care and its 'Big Conversation' are under way. The book offers examples of policy issues that carers' organisations around the world have examined, understood and worked to resolve. It shows how experience of caring challenges can be brought into the corridors of power to develop workable solutions.



Carers' Organisations and their Impact by Sue Yeandle is published by Policy Press, July 2026.

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FINDINGS

- The **world's first national carers' organisation was formed in the UK** (1965). From small beginnings, it rapidly achieved a national profile, and in the late 20th century, it chose also to support similar organisations around the world.
- It rapidly gained traction in the UK **as the media, public figures and ordinary citizens shared their stories of caring**, responding to its call for **fairness for carers**.
- Carers UK led the way on **working with employers** to help employees manage paid work and unpaid care, forming the vibrant Employers for Carers – the world's best example of such support.
- Carers' organisations proved **adept at proposing practical solutions** and have worked effectively over decades to promote positive change in multiple jurisdictions.
- **In the UK, they secured the world's first 'national carers strategy'**, an approach later emulated in other parts of the world.
- Mobilising at local, national and international levels, they shared ideas about policy developments to make life better for carers. The international carers' organisation IACO, formed in 2012, secured philanthropic business support, enabling it to **promote good-practice guidance at an international level**.
- **Eurocarers**, formed with UK carers' support, is today in effective and influential dialogue with EU policy makers.
- Carers' collaborations have produced **good practices and effective policies** in many countries, across Europe and in North America, Australia, New Zealand and parts of Asia.
- In the UK and globally, the carers' movement remains vibrant, committed and practical, working closely with governments to shape better policies and deliver **wellbeing outcomes**.

IMPLICATIONS FOR POLICY

Carers' organisations are 'carer led', with **unparalleled understanding** of what providing care means in real life. Policy makers must fully engage them in taking forward social care reform:

- A hallmark of their approach has been a **commitment to sharing carers' stories** and working with researchers to develop salient questions. **This approach is crucial for addressing today's care crisis.**
- They have worked to secure **robust findings on topics only governments and the state can fix**, taking that evidence to policy makers and parliamentarians with the aim of **finding workable solutions**.
- Carers' organisations have been **crucial innovators**, producing innovations in support for carers in different circumstances (e.g. caring for aged relatives, parent carers supporting a disabled child, young carers, carers seeking to combine their unpaid caring role with paid employment).
- Carers' organisations have **extensive knowledge and expertise** in finding solutions on: the **negative financial implications** of caring, and alleviating these; ensuring **recognition of carers** by the state, officials, employers and carers themselves, helping them seek **early support** before challenges escalate; developing **innovative local services** for carers, often at low cost, without expensive infrastructure; and **developing workforce strategies** that enable carers with paid jobs to balance their caring contribution with paid work in ways that underpin their long-term and immediate financial wellbeing.

Find out more:

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