

The Ethics of Caring in a Good Society: a national conversation

Initiated by Carers NSW

Conducted by St James Ethics centre

Supported by Macquarie Group Foundation

Laraine Toms

President Carers NSW

Why this project, why now?

- So much money on research ...
- So many services needed ...
- Why would Carers NSW do this?

Carers NSW: working in, and responding to, its environment

- We knew society was changing rapidly
 - More people needing care
 - Aging population
 - Changes in the nature of the family
 - Changes in the expectations of women
 - Fewer family members able to, or choosing to, care
 - More questions being asked about the physical and emotional costs of caring for a family member

Carers are at the frontline of care ... at the present

- Is the current caring scenario sustainable?
- What are the implications if it is not?

The big questions ...

What will the future hold for people needing care and their families?

What will this mean for society as a whole?



What do Australians want?



What's right? Who decides?

- Is it right that people have to give up education, jobs, financial security to care for a family member?
- Is it right that children sacrifice a childhood and education to care for a parent?
- Who should be responsible for caring?
- Should the taxpayer have to contribute to the support of a child with a disability when the parents knew the child would be born with that disability and made a decision to continue with the pregnancy?

The great questions of our time ... routinely reduced to matters for economic calculation

Dr Simon Longstaff, St James Ethics centre



Our vision – a different path

Our decision –

to engage the Australian community in a conversation about the fundamental values and principles which may be held by a good society, and the implications these values and principles might have on the way we as a society are, and could be, caring for our citizens of all ages who have a chronic illness, drug and alcohol dependencies, disability, mental illness or who are frail and aged.



What did we expect?

(Hope for!)

Engaging Australia through conversation with the issues –

- get people thinking, talking, sharing ideas

Addressing the crisis in caring now and in the future -

- informing the actions of individuals, governments, families, communities, the workplace

The Project

The researchers

- Who else but St James Ethics Centre?
Independent, globally respected, influential, ethical!

The funders

- Macquarie Group Foundation

An organisation with vision, belief in the value of the work,
committed to social inquiry

Why ethics and caring? What are ethics?

Socrates posed the question in the fifth century BC:

‘What ought one to do?’

In seeking to answer Socrates' question we are left with some enduring truths

Dr Simon Longstaff

Ethics is about relationships

- It's about struggling to develop a well-informed conscience
- It's about being true to the idea of who we are and what we stand for
- It's about having the courage to explore difficult questions
- It's about accepting the cost.

What is caring?

Defined for this conversation as:

- a sense of feeling and exhibiting concern and empathy for others;
- having a regard for others;
- protection; watching over or attending to;
- to feel concern or interest i.e. to care about;
- to feel love or liking for; and
- to take charge of, look after and to provide for.

What does the ethics of caring actually mean?

For the purposes of this national conversation, the ethics of caring is:

- Reflection and action in response to the question, 'What ought one to do' in relation to caring for others.
- When *caring* included an asterisk in our key question as in *caring** - it refers to caring for people of all ages who have a chronic illness, a disability, a mental illness or who are frail aged.

Project approach

- This project title includes the word *conversation*: this indicates it is not traditional research.
- This conversation is a gathering of as many voices as possible around issues related to Australia as a society and how it cares for its citizens.

The methodology nationally

- Focus groups – Four key questions asked
- Interviews – people not able to attend focus groups – elderly, disabled, aged care residents – same questions
- Conversation paper – by invitation – geographically remote areas, people under 25, to date unrepresented cultural and religious groups. The focus group discussions were summarised under the 4 key questions , the respondents were then asked to read the summaries then join the conversation
- Online survey open to everyone – questions organised from within areas covered by 4 key questions

Suzi Ross, and her assistant Antoinette Simon, from St James Ethics Centre, conducted all research. Carers NSW provided administration assistance.

Four key questions:

- What is a good society?
- What is caring*
- Who is responsible for caring?
- What does caring look like in a good society?

The conversation begins ...

Phase 1

Focus groups



Online survey

Phase 2

Material from all Phase 1 elements was collated, analysed and then used to design a national online survey which was a mixture of qualitative and quantitative questions, open to all.

Who participated?

- Corporate and small business sectors
- Media
- Public and private health and disability sectors
- Ethicists
- Medical practitioners
- Current and former carers
- Government/non government organisations
- ATSI communities
- CALD communities
- School children
- Religious representatives

Focus group 'snapshot'

If I tell you, will you hear me?

One focus group member spoke about the importance of the project conversations. The focus group was made up of family carers and she said that she hoped this project would increase people's awareness of not only the role of carers but also their daily experiences. It was not easy for any of the carers in the room to attend the focus group – they had to find someone willing and able to take over their role. As one of the carers said,

“It is a big battle we face day in day out and the bitterness we feel when asked about our situations. I understand why you need to ask – that’s why I have such a dilemma about these surveys: I hate doing them, but if I don’t how will you ever know and how will things ever change.”

Online survey

- Survey limited to those who had access to online services
- Long – some people took well over an hour to complete
- Complex conceptually
- Difficult decision making
 - Over 1000 people nationally completed it!

What they said a good society is

Natural clusters were identified:

- Equity, social justice human rights
- Respect
- Strategy and problem solving
- Safety, security
- Tolerance, diversity
- Reaching one's potential
- Care and compassion
- Responsibility and accountability
- Community and contribution
- Meeting citizens' basic needs
- Independence, self determination, autonomy
- Infrastructure and services
- Leadership
- Sustainability

And yet ...

- In the focus groups people agreed that caring was important in a good society, and identified 13 other characteristics
- In the online survey these characteristics, or descriptors, were listed and people were asked to select 4 from the 14
- The descriptor 'caring and compassionate' was chosen by less than 20% of online survey respondents.
- So who cares? Not many of us it would seem!



Sample survey questions

- Responsibility for caring for the care recipient – a list of 13 choices was given, including govt., family; religious institutions etc
- The question was repeated for family carers 'Who is responsible for caring for the carer?'
- And then again, 'Who is responsible for caring for professionals and care workers?'
- Who is responsible for funding caring – who should pay?
- Ethical dilemmas were posed and respondents asked to prioritise – decisions about competing rights eg the needs and rights of the 70 year old carer parent competing with the needs and rights of the 45 year old son with a disability

What is caring*?

- 'Caring is the highest calling in society; it is the willingness and ability to make sure that all people are valued and are able to maintain their dignity as human beings; caring is honoring the humanity in people whose physical or mental or aged circumstances place them at the margins of society; it is responding to need.'
- 'The basis of any care giving is a focus on relationships.'
- 'It's what makes us human.'

Relationship challenges

Focus group snapshot

'I had to apply for a Carers' pension – I couldn't understand the interviewer – she was from another country and had a strong accent. My husband was angry and bored with all the questions she was asking. He said 'she wipes my arse for me too' and walked out. I had to start again.'

Caring* involves decisions

'The duty to do good and avoid doing harm – which is part of many professional codes in the health sector – can be very confusing as to what causes harm. There is the obvious aspect of keeping people safe and secure where it would be harmful to do otherwise. There are situations where various interventions would avoid harm; these need to be balanced against respect for patients' rights to refuse these interventions.'

'I would prefer to tailor care to individual needs but I feel bound by the system, also by fears of litigation.'

'The regulations do not consider individual aspirations and are more about bureaucratic control and political protection than care delivery.'

Who is responsible for caring?

The answer was all of us, with different but interrelated roles.

'For the individual this accountability firstly stems from their responsibility to themselves in terms of prevention – engaging in measures to avoid preventative chronic illnesses caused by poor lifestyle choices, eg diet.'

'Am I old fashioned? I think family has the primary responsibility.'

'What about those who have no family? And those who are ostracized by their family?'

So who should be responsible?

'Everyone might have a caring responsibility at some point in time but government should have the role of organising and supporting.'

'The local community ...'

'Local government ...'

'The workplace and corporate sector ...'

'Federal government ...'

What does caring look like in a good society?

Three core elements emerged:

1. People would have quality relationships
2. People needing care would be cared for, as would their carers
3. Caring would be government enabled and community centred

For a care worker – ‘adequate remuneration’

For an individual – ‘a society in which I’m happy to grow old’

Just a thought ...



The narrative

Phase 3

The narrative is published and available on our website:

www.carersnsw.asn.au

The conversation continues ...

We have just begun. Now we know what Australians believe is right. What they want for the future. The evidence is in. Australians in all their diversity have reflected, discussed, argued, joined focus groups, completed online surveys and made their contributions to the conversation. Their recommendations are clear.