

A PERICLES FILMS PRODUCTION

# On Richard's Side

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## Screening and discussion guide



**“If we have a notion that there is something in humanity that is intrinsically worthwhile and valuable and that people who call forth our caring and our love and our compassion are doing a service to us because those are qualities that enrich our humanity...then without people who are vulnerable, without people who need us, how do we practise our caring and our compassion?”**

**—*Deirdre Croft***

In conjunction with our website, this Screening and Discussion Guide is intended to help you host a screening of *On Richard's Side*.

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# 01 | film synopsis



This story begins thirty-five years ago when Richard was born in 1980, revealing through home movies and footage from the previous films how Richard's mother Deirdre coped caring for Richard as a lovable child who also had highly erratic and often violent impulses. It also reveals the strong bonds that grew between a father and son when Richard's dad, Charlie, became his sole carer for eighteen years.

Deirdre, now in her early sixties, is again her son's primary carer and she must plan the remainder of both their lives. We witness the extraordinary day-to-day effort required to look after Richard and Deirdre's fierce determination to build a circle of friends and carers for him in case anything happens to her.

Deirdre's efforts to find a sustainable, long-term accommodation solution for Richard take them both an emotional journey which is exacerbated when Richard's behaviour becomes unpredictable and his health deteriorates. Deirdre is resilient but the toll on her becomes apparent as she fights to create and put in place a good life for her son.

The leading voice of this film is the fearless and impassioned voice of Deirdre and that voice, just one of many, tells us that to care for someone means to care for life. Amidst the immense struggle, the film reveals moments of humour and great tenderness and how, in many ways, Richard gives to others even as he receives their care.

## 02 | the film maker

Andrew Wiseman has worked as a producer and director for over thirty years. Combining drama and documentary work he has created award-winning productions for Australian and international audiences. With a particular interest in the interplay between historical events and the present, recent drama titles include *Parer's War* (2014),

*Sisters of War* (2010) and *Curtin* (2007). In his trilogy of documentaries, Wiseman aimed simply to provide a canvas for Richard and Deirdre to tell their story. The film uses an observational and non-interventionist approach, letting the rawness, joy, honesty and enormous challenges that confront them both to be laid bare.

### An interview with Andrew Wiseman

#### How did you find Richard's story?

I met Deirdre in 1989 whilst working at the Film and Television Institute in Perth. She had an idea for a film about mothers who had children with disability. After I spoke with her and met Richard I thought their story was really worth telling and deserved to be told. Twenty-seven years and three films later I hope part of their story – a story about caring and love and dedication – has been revealed.

I've been asked a number of times what *On Richards Side* is about - what's the core of the film? There's no one right answer to that question of course but for me the film is about the place of caring in our society. All of us are touched by care. You're either someone who is cared for or will be cared for. You're currently a carer or will become a carer. Surely how we deal with and respond to questions surrounding care are critical markers of how we are succeeding as a country – whether we are just and fair.

#### Why did you decide to make this documentary into a trilogy?

Some projects take longer than others. I began filming *Driving with Richard* in 1989. *On Richard's Side* was completed in early 2016, so it's been quite a journey.

*Driving with Richard* focused on Deirdre's relationship with Richard and then ten years later I made another film called *Wonder Boy* which focused more on Richard's relationship with his dad, Charlie, who was Richard's primary carer for eighteen years.

Fast-forward fifteen years and I had a phone call from Deirdre saying that there had been a major change in Richard's life, and in hers, and there was now a compelling reason to.

The first two films were a TV hour in length but this third film is feature length – approximately 97 minutes. The extended length of this film has allowed me to weave footage from the first two films and previously un-used footage to tell the contemporary story, one in which Deirdre asks the question, what will happen to Richard if she is no longer able to look after him? Deirdre is determined to find suitable long-term accommodation for her son because, as she says, there are seasons in a life and it's time to transition into the next season.

#### What have you learnt across the making of the three films?

I have seen at close hand how Richard, who is non-verbal and requires a great deal of care, gives to others in many, many ways even as he is being cared for. These relationships are reciprocal and not just about someone looking after someone else. I have witnessed Deirdre and her family and circle of friends and support workers caring across three decades. And so I have seen how caring needs to be shared and shared across a life time.

Crucially, I have seen how if caring is not supported adequately the effort required by an individual cannot be sustained at a healthy level. And that support needs to be wide and consistent – from government and community and friends and business and support organisations. And I have seen how the nature and intensity of caring changes, sometimes very rapidly – and so planning needs to be in place to deal with those changes.

## 03 | the issues

“There are only four kinds of people in this world—those who have been caregivers, those who currently are caregivers, those who will be caregivers and those who need caregivers.”

—Former First Lady Rosalynn Carter



Anyone, at any time, could be a carer. Over the life course, all of us will receive care, most of us will provide care and many of us will both receive and provide care at multiple points in time. Caring activities are ‘central to the functioning and sustaining of society and the economy through the provision of an invisible workforce that augments the aged, disability, mental health, palliative and community care systems<sup>1</sup>. Some people are thrust into the role without warning, for others it may be a more gradual process. Some as young as six, others in their 70s. Whilst every care situation is different, caring incurs significant emotional, financial and health costs for the care-giver.

With advances in healthcare, the elderly, chronically ill and those with disabilities are now living longer at the same time as the

working age population is decreasing in relative terms. As the proportion of Australia’s population aged over 65 continues to increase Australia will soon reach the ‘tipping point’ for care, when there are likely to be fewer unpaid carers relative to the ageing population.

The number of Australians currently providing unpaid informal care and support for a family member, relative or friend is over 2.8 million. If they all stopped providing that care, for whatever reason, we would have to find an additional \$60 billion in our economy each year to pay people to replace the care provided by carers.

*On Richard’s Side* presents a story about a mother and her son and their extended family. That’s the specific story but the universal themes ripple out. Whether the care relates to someone with a complex disability like Richard’s or it’s about care for someone who is aging or who has a mental illness or chronic condition, one person taking the whole load is not sustainable.

We hope *On Richard’s Side* will help raise the profile of carers in our society and spark conversation about the various ways we as a community can provide much needed emotional and practical support to caregivers. We need to be caring more of our carers. Caring is universal. Interdependence is in our DNA.

## 03 | the issues

# 75

the average wellbeing score for Australians

# 58.5

the average wellbeing score for carers in Australia

### The Impacts of Caring

#### Health & Wellbeing

For many, keeping their partner or parent living at home as they age is a priority. While they might find joy and satisfaction in providing care for someone who needs extra help and support, it can also be stressful and exhausting – especially if they're getting older themselves.

The largest Australian survey of carer's health and wellbeing found carers had the lowest wellbeing of any population group surveyed to date and that more than a third had severe or extremely severe depression.<sup>2</sup>

Wellbeing is defined by the Australian Centre for the Quality of Life as 'a stable state of being well and feeling contented'. The average wellbeing score for Australians is 75, for carers in Australia it is 58.5.<sup>3</sup>

Studies have indicated that physical exercise can help improve mood but it can be difficult to find the time to exercise when one is busy looking after another person, particularly when people have an illness or increased frailty that stops them from exercising the way they used to.

The National Ageing Research Institute's IMPACCT research project aims to investigate whether an exercise programme done at home can help support both carers and their care recipients.<sup>4</sup>

#### Social Exclusion

Caring is solitary by its nature and carers often report feelings of isolation because their caring responsibilities result in a reduced ability to participate in activities outside their caring role. They are more likely than the general population to have little face to face contact with friends or relatives outside the household especially when caring for someone with high level care needs.<sup>5</sup>

The availability of respite is therefore an important support which enables carers to have a break. Women are less likely than men to utilise respite services<sup>6</sup> which can perhaps be attributed to the societal expectation that women take on and accept caring responsibilities as part of a stereotypical woman's role.

#### Financial Disadvantage

Contributing to the high stress levels and low wellbeing is the fact that carers experience a high level of financial stress. Carers are twice as likely as is normal to worry that their income will not be sufficient to meet their expenses.<sup>7</sup>

Around 30 per cent of families receiving carer benefits experience difficulty in paying utility bills compared to 14.6 per cent of the general population.<sup>8</sup> This is not unexpected given that the average household income of a carer is much less than that of the general population.<sup>9</sup>

## 03 | the issues

The financial support a carer receives varies according to their circumstance but is significantly lower than the average minimum weekly wage. To be a carer to a person with a disability, chronic illness, mental illness or of frail age is not economically valued. Tied to paid employment, the superannuation system financially disadvantages people who take time out of the workforce to care for others, and in Australia that affects more women than men. Without superannuation, carers become dependent on the aged pension provided by the government to support their needs in their retirement years.

The financial impact of the caregiving role is likely to be most pronounced on mothers of a child with a disability, forgoing education and employment opportunities spanning across much of her potential working life.<sup>10</sup>

### **Work & Caring**

People are most often parents by choice but they are often carers by fortune.

In Australia, broadly speaking, access to parental leave schemes, flexible work conditions and provisions for child care assist parents to combine work and unpaid care. Employment laws prescribe as a minimum under the National Employment Standards that requests for flexible working arrangements be available to parents or carers under school age or a child under 18 with a disability. What of other types of carers? Generally Australian workplaces do not adequately support the needs of carers of people with disability, chronic illness, mental illness and frailty, providing only short-term relief, under the general category of personal leave.

An employee can become a carer at any time – such as when a family member has an accident or acquires an illness or disability or when an ageing parent becomes frail. 12% of all working Australians are carers, in all manner of occupations and industries.<sup>11</sup>

As the proportion of the workforce who have a caring role increases, it becomes essential that employers provide carer friendly workplaces by implementing policies and procedures which support employees to manage both work and care.

Supporting carers benefits both employer and employee including in the following ways:

- > reduced costs of employee turnover
- > increased productivity
- > reduced employee stress and absenteeism
- > increased staff morale.

### **Carer Awareness**

One of the biggest hurdles in the unpaid caring debate across the globe is the stigma associated with caring itself.

Raising awareness about carers across an organisation is important to help employees 'self-identify' as a carer. Education and information can take a variety of forms including online resources, workshops, seminars, carers' networks or forums.

Ultimately the caring of a family member with a chronic illness should be seen by colleagues as equally worthy as caring for a newborn. In the work environment, for myriad reasons carers often choose not to broadcast their caring responsibilities. It may be in anticipation of negative perceptions or choosing to keep work separate from care, rather than trying to balance the two. What is most important is that the workplace culture is carer friendly, such that if and when the carer wishes to discuss their caring responsibilities, they do so knowing they're supported by management and colleagues.

### **Young Carers**

Young carers are children and young people up to the age of 25 who care for and support a family member who has a long-term physical illness, mental illness, disability, drug or alcohol problem. In Australia, a growing

## 03 | the issues

number of children and young people have responsibility for a high level of care in their home because of a family member or friend's disability, illness, mental illness, frail age, or drug or alcohol problem.

**There are more than 390,000 young carers under the age of 26 years in Australia of whom 170,000 are under 18 & nearly 80,000 (1.7%) under 15**

**The average age of a young carer in school is 12-13 years old.**

**Young carers are equally likely to be male or female**

**There is a higher prevalence of caring amongst young people from culturally and linguistically diverse background.<sup>12</sup>**

These figures are likely to be a significant underestimate due to the number of 'hidden' young carers and are projected to rise along with increases in the prevalence of disability and single-parent households.

A reluctance or inability to self-identify applies equally to young carers. The reasons why young carers remain a hidden group vary. For some it is social and cultural values, beliefs and attitudes that result in a lack of self-identification, for others, school is the one normal part of life and they don't want everyone to know about their caring role.

Moreover, many of these young people wouldn't think of themselves as a carer because what they do is just part of their normal daily life and routine. Some have been caring from as young as six or the family member they care for may have only recently become ill. On average there are likely to be 2 or 3 young carers in every classroom<sup>13</sup>. Many young carers may not ask for help because they're afraid that someone will think they're not coping and that they should be removed from the family.

Whilst sharing information about their home life can sometimes be difficult, young carers need to know there is a wide range of supports and services available to them. Teachers, counsellors, youth workers and health professionals a School staff all have a great capacity to provide support, guidance and mentoring to children and young people, particularly those experiencing difficulties. Many young carers report that teachers can have a huge positive impact on their lives just by being aware of their care situations, by listening to them and linking them with suitable supports.

Recently FACS, Carers NSW and young carers worked with developers to design an accessible and age-appropriate tool for young people with caring responsibilities.

The free app 'Who cares?' encourages young people to identify as carers and to get the support that is right for them, when they need it.

1 NHHRC 2009

2 Carers Australia, *Work and Care Guide for Employers*

3 Cummins et al *The Wellbeing of Australians – Carer Health and Wellbeing*, Deakin University 2007

4 NHMRC & NARI 2016 The project will be completed by end of 2016

5 Australian Institute of Family Studies and FaCSIA 2007, *The Families Caring for a Person with a Disability Study and the social lives of carers*

6 Vecchio, *Understanding the use of respite services amongst informal carers*, Australian Health Review 2008

7 Cummins et al *The Wellbeing of Australians – Carer Health and Wellbeing*, Deakin University 2007

8 Edwards et al *The nature and impact of caring for family members with a disability in Australia*, AIFS 2008

9 Cummins et al *The Wellbeing of Australians – Carer Health and Wellbeing*, Deakin University 2007

10 *Lifetime economic consequences to women informal carers in Australia*, National Centre for Social and Economic Modelling, University of Canberra, 2006

11 Carers Australia, *'Work & Care, The Necessary Investment'*

12 Carers Australia & Deloitte

13 Carers Australia *'Young Carers in Education'* 2011

# 04 | some fast facts

# 1 in 8      60.3

number of Australians providing informal unpaid care

the annual cost, in billions of dollars, of replacing unpaid care with services provided by formal care providers

## Who is a carer?

A carer is someone who provides unpaid care and support to a family member or friend who has a disability, a mental illness, chronic condition, terminal illness, an alcohol or other drug issue or who is frail aged.<sup>14</sup>

## How many people are carers?

In 2015 there were over 2.8 million Australians providing informal unpaid care, which is the equivalent of one in eight.<sup>15</sup> Of that figure, 825,000 are primary carers, providing the majority of the recipient's care.<sup>16</sup>

Although nearly 3 million, provide unpaid care, many don't necessarily see themselves as carers. One in every eight employees in the workplace is a carer.<sup>17</sup>

## Age

Most carers are aged between 35 and 54.<sup>21</sup> Nearly 20% of carers are over 65

There are almost 400,00 young carers under the age of 25 in Australia. Of these, 23,200 are primary carers.<sup>22</sup>

## Number of hours of care provided

An estimated 1.9 billion hours of unpaid care was provided by Australian carers in 2015.<sup>18</sup>

## Valuing carers

In 2015 the annual cost of replacing unpaid care with services purchased by formal care providers was estimated to be 60.3 billion.<sup>19</sup>

## Carer demographics

Around 37% of carers who provide more than 40 hours of care per week have been in this role for 10 years or more.<sup>20</sup>

## Gender

Women make up the majority of primary/informal carers in Australia (69.7%) and 56.1% of all carers. 25% of all Australian women in their fifties are carers for someone.<sup>23</sup>

Across all age groups (15-64) less than 23% of women primary carers of people with disability, frailty or chronic illness participate in full time employment at any point.<sup>24</sup>

14 Carers Australia

15 Australian Bureau of Statistics 2012 *Survey of Disability, Ageing and Carers*

16 Deloitte Access Economics 2015, 'The economic value of informal care in Australia in 2015'

17 Australian Bureau of Statistics 2012 *Survey of Disability, Ageing and Carers*

18 Deloitte Access Economics 2015, 'The economic value of informal care in Australia in 2015'

19 Deloitte Access Economics 2015, 'The economic value of informal care in Australia in 2015'

20 Australian Bureau of Statistics 2012 *Survey of Disability, Ageing and Carers*

21 Deloitte Access Economics 2015, 'The economic value of informal care in Australia in 2015'

22 Deloitte Access Economics 2015, 'The economic value of informal care in Australia in 2015'

23 Deloitte Access Economics 2015, 'The economic value of informal care in Australia in 2015'

24 Australian Bureau of Statistics, 'Employment conditions', *Gender Indicators, Australia*, Jul 2012,

## 05 | screening discussion guide



We hope *On Richard's Side* will be a springboard for deeper engagement and that audiences will reflect on what they've seen with colleagues, peers, family and friends.

The questions on the following page have been designed so that the audience has the opportunity to share their personal and/ or professional views, feelings and experiences. Some may be more appropriate than others depending on your audience.

# 05 | screening discussion guide



## General questions

Are you currently caring for someone in your family or a friend?

Are you aware of any carers in your workplace?

What were some of your thoughts and feelings during the film?

What particular moments / scenes affected you the most and why?

What questions did the film raise for you professionally or personally?

Andrew Wiseman believes that how we deal with and respond to questions surrounding care are critical markers of how we are succeeding as a country – whether we are just and fair. Do you agree?

Do you agree with Deirdre that we need people who need us, who are vulnerable, so as to practise our caring and our compassion?

Deirdre describes caring as a health hazard, and at one point declares that she is 'absolutely exhausted'. How can we better care for and support carers?

## Specific questions

Do you agree that we as a society undervalue (and exclude) the people who are contributing so much to it, if so how can we end the stigma of care?

It was only after Charlie's death that Deirdre started making plans for Richard. What keeps us from making arrangements in advance of our own ageing and eventual demise?

Australia has very generous maternity and parental leave provisions based upon caring for a newborn or adopted child. Should carers' leave be viewed in a similar way?

There is a gender divide in caregiving. Consistent with the national statistics, women are the primary caregivers. Do you think this is a choice or an obligation? What's the difference between the two? Why do you think women tend to take on caretaking roles?

Charlie was fortunate to have Blue as a mate. There are many male carers who remain more hidden. What do you think would help support and recognise male carers?

# 05 | screening discussion guide



## **A carer's guide to what NOT to say (vs what to say)**

Caring can change your life, it can often change relationships too. Sometimes family and friends might visit you less often because they think you have too much to do or they don't know what to say.

### **What NOT to say - 'It could be worse'**

That may be true but recognising that it could be worse is frightening, what will you say then?

### **What to say - 'I don't really know what to say right now, but I'm here if you need me.'**

Simply acknowledging that the situation is difficult can be comforting. During times of crisis, what a caregiver often needs is presence — the presence of a family member or a close friend — not pity, not small talk, just presence.

### **What NOT to say - 'I haven't phoned but you know where I am'**

Does your phone only accept incoming calls? Unintentional it may be but the comment is insensitive. Just a few minutes of friendship means so much to most people.

### **What to say - 'I've been thinking about you. Would you have time for a visit this week? You name the time and place.'**

Caregiving can be lonely at times. Some people who feel uncomfortable stay away, and caregivers have little time to go out. Reminding a caregiver that you are still a friend and allowing the caregiver to arrange to meet when and where it's convenient is respectful and compassionate.

### **What NOT to say - 'Oh we didn't think you would be able to come'**

That may be true but an invitation would let the person know that you still care, and that they are still part of your life.

### **What to say - 'I am bringing XX with me to mind your son while I take you out for lunch, will Saturday at 1pm be OK with you?'**

Sometimes it's better to take the guesswork out of things.

# 06 | the impact campaign

*On Richard's Side* has the active support of leading not for profits, philanthropists and individuals, who like us, believe in the capacity of film to galvanise social change.

The objectives of our impact campaign are that this compelling story will:

- > raise awareness
- > generate conversation
- > create a stronger movement
- > drive social change

### Changing hearts and minds

Working alongside our key stakeholders in the caring and training sector, screenings of *On Richard's Side* (the feature length documentary) and *Time to Care* (a shorter version) will be held across Australia and internationally.

The 'changing minds' screening opportunities for the films include:

- > Film Festivals, in Australia and internationally including Disability Film Festivals
- > National Carers Week, October 2016 & 2017
- > Campaign partner screenings and community screenings
- > Facilitated regional and metropolitan community screenings with moderated Q&A
- > Educational screenings for professional development of paid support workers
- > Parliament House Screenings – Canberra and nationally

### Building communities in the workplace

One of the key themes of the film is that caring for someone across a lifetime often includes the challenge of combining work and care. There is significant evidence that implementing flexible work options optimises resources and



productivity. We are hopeful that corporate screenings of *Time to Care* and *On Richard's Side* together with focus groups and education programs will help more organisations to 'mainstream' flexible work options as standard business practice.

### Training

*Time to Care* will be used by many of our partners such as YMCA and NDS as a training resource for support workers and trainees.

### Education and Young People

Our aim is for the feature length documentary to be used as a curriculum resource for Year 8 students in 2017, accompanied by a specialist study guide, to generate conversation around the issues of young carers in schools. Applicable syllabus subject areas include Ethical Understanding, Civics & Citizenship and Personal Social and Community Health.

# 07 | what's next

**Take our short online survey**  
[surveymonkey.com/r/X5YJNPW](https://surveymonkey.com/r/X5YJNPW)

**Subscribe to our mailing list**  
Visit [onrichardsside.com.au](https://onrichardsside.com.au)

**Support our outreach initiatives**  
Email [info@onrichardsside.com.au](mailto:info@onrichardsside.com.au)

**Join the conversation  
on social media**

 [/onrichardsside.com.au](https://www.facebook.com/onrichardsside.com.au)

 [@onrichardsside](https://twitter.com/onrichardsside)

 [onrichardsside](https://www.instagram.com/onrichardsside)

## Volunteering

Consider volunteering for a carer association - there are many ways to get involved, as Ambassadors and Mentors, assisting with Carers Week events, fundraising activities or office administration

## Resources

**Carers Australia ([carersaustralia.com.au](https://carersaustralia.com.au))** is the national peak body advocating on behalf of Australia's 2.8 million carers

It runs the Young Carer Information, Advice, Support and Referral program and works closely with the Commonwealth Respite and Carelink Centre

**The Commonwealth Respite and Carelink Centre** is a 24 hr, 7 days a week service for carers and their families 1800 052 222

**Youngcarers.net.au** is the Carers Australia website designed for young carers, their families and people working with them

**Reachout** – [reachout.com](https://reachout.com) is a national website for young people about issues which affect their lives

**Carers Australia and the Network of Carer Associations** can also provide information on counselling, support groups and ways to connect with other carers

**Carers ACT** ([carersact.org.au](https://carersact.org.au))

**Carers NSW** ([carersnsw.org.au](https://carersnsw.org.au) / [youngcarersnsw.org.au](https://youngcarersnsw.org.au))

**Carers NT** ([carersnt.asn.au](https://carersnt.asn.au))

**Carers Queensland** ([carersqld.asn.au](https://carersqld.asn.au))

**Carers SA** ([carers-sa.asn.au](https://carers-sa.asn.au))

**Carers Tasmania** ([carerstas.org.au](https://carerstas.org.au))

**Carers Victoria** ([carersvictoria.org.au](https://carersvictoria.org.au))

**Carers WA** ([carerswa.asn.au](https://carerswa.asn.au))

The **Carer Gateway** launched by the Australian Government provides information about services and support available to people who care for someone with a disability, chronic illness, dementia, mental illness or frailty due to age. [carergateway.gov.au](https://carergateway.gov.au)

# 08 | our supporters



*On Richard's Side* is grateful to the following Impact Campaign partners and supporters:

## Campaign Partners



Ai-Media  
Antoinette, Emily & Anna Albert  
Australian Women Donors Network  
Phillip Cornwell  
Creative Partnership Australia

Crown Resorts / Packer Family Foundation  
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Doc Ross Family Foundation  
The Vasudhara Foundation

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Australian Human Rights Commission  
Carers Australia  
Carers ACT  
Carers NSW  
Carers NT  
Carers QLD  
Carers SA  
Carers TAS  
Carers VIC

Carers WA  
FACS  
Foundation for Young Australians  
Future Living Trust  
Human Rights Law Centre  
Moores Legal  
Mirabel Foundation  
National Disability Services  
YMCA