

‘Who Cares’ Discussion Guide

This discussion guide accompanies the book *‘Who Cares: the Hidden Crisis of Caregiving and How We Solve It’* by Emily Kenway. The book blends the lived experience of the author as an unpaid carer/caregiver with interviews and in-depth research to explore and explain the state of unpaid care today.

It contains discussion questions for each chapter loosely designed according to Bloom’s taxonomy for learning objectives, two small group exercises, and overarching essay questions.

Discussion Questions for Chapters

CHAPTER 1: On Caregivers: Missing Stories, Missing Solutions

This chapter provides an overview of what ‘care’ means; what impact it has on people’s lives today; and historical political context for that impact.

Knowledge

- When we talk about ‘family carers’ (UK) or ‘family caregivers’ (USA), what and who do we mean?
- How does being a carer/caregiver affect people?
- Identify and discuss the themes in the stories of real people in Chapter 1, including examples from the Global North and the Global South.

Application

- Drawing on what you know from Chapter 1 about how care affects people, consider your own life and what would happen if next week you became a carer/caregiver – what might change and how might different parts of your life be affected?
- Drawing on the experiences discussed in Chapter 1, when do people ignore carers/caregivers versus act supportively and campaign for their interests?

Critical and Creative Thinking

- Why might family carers/caregivers be needed even with paid care workers involved in someone’s situation, and what might this mean from a policy or campaigning perspective?
- Chapter 1 describes the impact of care on people’s lives. Evaluate the different domains of impact and make a case for which area should have intervention first.

CHAPTER 2: On Women: Maidens and Migrants

This chapter explores the relationship of gender and race to care.

Knowledge

- How do men and women differ in the ways in which they are involved with caring?
- What did the ‘wages for housework’ campaign seek to win?
- What are the ‘two categories of women’ explained in this Chapter?

Application

- Explain the case of Thomas Grant’s wife in 1875 and Martha Sonnicksen in 1937 and what they tell us about gender views in the past.
- What are ‘global care chains’ and how does this affect contemporary approaches to providing care in different countries?

Critical and Creative Thinking

- Drawing on what the Chapter explains, how might you argue that race is a key factor in shaping people’s roles in relation to care?
- Are women especially well-suited to providing care, whether paid or unpaid, or is this a cultural construction?
- What would a gender just, and racially just, approach to care look like?

CHAPTER 3: On Technology: Sleepwalking and Sealpups

This chapter explores the relationship of technology to care, including cutting edge ‘carebots’, and ethical and political concerns.

Knowledge

- What kinds of technologies are carers/caregivers already using and why?
- What is ‘skin hunger’ and why is it relevant to technology and care?
- How does working time relate to carers’/caregivers’ use of technology?

Application

- If you were a carer/caregiver, which technologies would you find useful?
- Consider the examples of Monica using ElliQ and of people in elderly homes using PARO the seal: what are the cases for using technology in these two different settings?
- Of the ‘technoethical’ categories listed, which ones feel most important and concerning to you?

Critical and Creative Thinking

- Evaluate the importance of having human-led care versus robot-led care – in what ways is care affected differently and what do you think about this?
- Formulate your own proposal for ethical guidelines for the development and use of technology in care settings.

CHAPTER 4: On Family: Wise Women and the Practice of Kinning

This chapter explains changes to family structures and proposes new ways of thinking about family and care.

Knowledge

- How are family patterns changing and how does this affect care?
- Who were the beguines and in what ways does the chapter suggest they're relevant when we're thinking about caring arrangements?
- Explain the example of 'OWCH' and why it's relevant to considerations of care.

Application

- Why might marginalised groups have cultivated different types of caring bonds than the traditional family?
- Consider your own family history – can you see the patterns described playing out there or not?

Critical and Creative Thinking

- Discuss the examples of reimagining the family in the chapter and your own feelings about this idea.
- What do we mean when we talk about 'family'? Critically discuss at least two of the following concepts in your answer: reciprocity, obligation, kinship, love.

CHAPTER 5: On the Mind: Confronting a Convenient Stigma

This chapter explains the mental health impacts of care and how cultural bias shapes them.

Knowledge

- What does 'caregiver stress syndrome' mean and what does the chapter describe it feeling like?
- What kinds of mental health issues afflict carers/caregivers?
- Explain disease avoidance theory and how the author suggests it relates to care.

Application

- In what ways are friendships and romantic relationships described as being affected by care?
- How do social and/or romantic relationships relate to our mental wellbeing, and how are carers/caregivers affected in relation to this?
- If we avoid signifiers of disease, how might this affect social behaviour towards carers/caregivers?

Critical and Creative Thinking

- Critically discuss the idea that we should be able to control how much care we must perform and the extent to which it impacts our lives, using examples from the chapter and your own ideas.
- If stigma and bias are evolutionary, to what extent do you think we can change them?

CHAPTER 6: On Freedom: The Lie of the Individual

This chapter explores ideas of freedom and interdependency and how they affect individual and collective caring experiences.

Knowledge

- Describe Hope Landrine's analogy of the billiard ball. How does this relate to care?
- What are the key points being made in the extract from Carlyle Brown's play?
- Describe Hilary Cottam's Circle project and share your views about it.

Application

- The chapter argues that neediness is seen as negative in our culture. Can you think of examples of this from your own experience and knowledge?
- If we think that being vulnerable is shameful, how might this affect our behaviour when we are unwell and need care?

Critical and Creative Thinking

- Are we free or are we interdependent? Choose one or the other and argue your case.
- Are there flaws in allowing communities to create support structures without government oversight? Consider this question in relation to what we've learned from the book about racial and gender disparities.

CHAPTER 7: On Work: Breadwinners or Caregivers

This chapter explains how work and care intersect and proposed changes to working styles to support a caring society.

Knowledge

- Using the descriptions in the chapter, what is it like to be a person who is both working and also providing unpaid care to a loved one?
- Many people are parents as well as workers, and many people are carers/caregivers as well as workers. Describe the similarities and differences between these two groups.
- Describe the 3 changes the chapter says we need to make to the work world accommodate care.

Application

- Explain the cases of Katy in the UK and Line in Norway. What has been different for them and why? What has been the same and why?
- Is it important for carers/caregivers to stay in work? Argue your position.
- If you were a worker and a carer/caregiver in the future, what kinds of support and policies would you want?

Critical and Creative Thinking

- Contrast and explore the idea of care as a 'sector' versus care as a 'species activity'.
- Evaluate the 3 changes the chapter says we need to make to the work world. Do you think these would work or not? Why haven't they happened already? What are the risks and benefits?

CHAPTER 8: On Government: Commoning the Horizon

This chapter explains different models of governance for care and proposes a 'commons' approach.

Knowledge

- What rights does the chapter argue we need to be given by government
- Why do carers/caregivers need income support? What are some of the ways this can be provided, according to the chapter?
- What is meant by a 'commons' in general and in relation to care?

Application

- Drawing on ideas in the chapter, how would your local neighbourhood and home environment shape your experience as a carer/caregiver?
- The Chapter explains 3 different ways of positioning care: as a public concern, as a private issue, or as something to be dealt with by a 'commons of care'. How do these positions differ?

Critical and Creative Thinking

- The chapter argues that we lack local social structures which could be important for care. Do you agree? If so, why do you think these structures are lacking?
- Do you think care is a public, shared concern or something which should be kept within and dealt with in private? How would your position affect policies and support for carers/caregivers?

Exercises for Small Groups

1) Exploring impacts and intersectionalities

This exercise is designed for classes to break into smaller groups. It asks them to recall and apply their new knowledge learned from '*Who Cares*' and any other texts to think through how care affects people in our society, with a particular focus on intersectionality and policy change. You could use all the questions or break it into smaller parts.

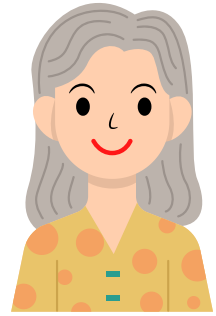
Overleaf, there are 4 simple case studies of carers/caregivers. Groups are asked to read/listen to these and consider the following questions:

- What impacts might care be having on each of these 4 people? Consider differences between them, and differences over time too.
- How might their differing characteristics be shaping their experiences and the impacts they feel? Consider race, migration status, gender, age, social status, stigma and any else you feel is relevant.
- What kinds of policies, interventions or other supportive measures might be beneficial? Consider whether those would need to come from government, employers, communities, or other sources.

Case study 1: Elaine

Elaine is a 45 year old white woman who works as a cleaner. She was born in the country she lives in, and is a citizen, not a migrant.

Elaine is caring for her father, who is 80 years old, and has dementia. He is physically fit but cognitively impaired.



Case study 2: Emma

Emma is a 15 year old Black girl who goes to school. Like Elaine, she is not a migrant and has full citizenship. Emma is caring for her mother who has bipolar disorder.

Case study 3: Edward

Edward is a 75 year old white man with type 2 diabetes. He is a migrant but he has had citizenship for over ten years. He works as an accountant. Edward is caring for his husband who has terminal cancer.



Case study 4: Esmeralda

Esmeralda is a 30 year old Roma woman with no formal employment. She is seeking asylum. She cares for her daughter who is 3 years old and has Down syndrome.

Case study insights for teaching staff

Case study 1: Elaine

- Her work as a cleaner is likely to mean she experiences limited power at work, may be precarious and subject to short notice schedule changes. This will affect her ability to juggle work and care (Chapter 7).
- She is likely to earn a low income and therefore will feel the financial impacts of care more harshly than someone with a higher income and more savings. This may have a knock-on effect on her quality of life in older age due to a lack of pension savings (Chapter 1).
- Her father is physically fit but cognitively impaired, and therefore may live for a long time with intensive care needs. This may make Elaine at higher risk of mental health impacts (Chapter 5).
- We do not know about Elaine's other relatives; students may hypothesise about the presence or absence of others, as per Chapters 2 (in relation to male relatives) and 4.
- *Policies for Elaine: rights to flexible working, rights to income protection for caregivers, rights to paid job-protected care leave from work, rights to respite breaks for carers, access to mental health support, social security credits for time spent caring and not earning*

Case study 2: Emma

- As a young carer, Emma is likely to miss out on important aspects of school life, mimicking the women's histories described in Chapter 2.
- Emma is likely to be subject to social ostracisation and isolation (Chapter 5, particularly Safa's case).
- As a Black girl, Emma may experience racialised impacts, for example being expected to be 'natural' at care (Chapter 2) and being less comfortable accessing government services (Chapter 8).
- Emma's mother has a mental, not physical, disorder. She may experience greater stigma and less understanding (Chapter 5).
- *Policies for Emma: support schemes for young caregivers, improved school awareness of students being caregivers, respite breaks, education in school curricula about care, mental health and stigma, access to mental health support, effective inclusion practices in government provided service*

Case study 3: Edward

- Edward is gay and may therefore be concerned about using government services (Chapter 8).
- Edward has his own pre-existing health condition which may be exacerbated by caring tasks and may limit his caring abilities (Chapter 1).
- Edward works as an accountant, suggesting a higher degree of power and income than other cases, so he may be better able to absorb the financial impacts of care (Chapter 1).
- Edward may be accustomed to drawing on ‘fictive kin’ for support due to his LGBTQ identity, which may mean he has more support on hand (Chapter 4).
- *Policies for Edward: Effective inclusion practices in government provided services, enhanced access to medical treatment for caregivers (for example, out of hours appointments, flexible appointment systems, at-home visits)*

Case study 4: Esmeralda

- Esmeralda is an asylum seeker which will mean she has limited access to government services and support (Chapter 8).
- Esmeralda may experience xenophobia and racism in her daily life, which will make the impacts of care harder to cope with (Chapter 1).
- Esmeralda’s daughter will, hopefully, live a long life, meaning Esmeralda will be caring for the rest of her own life too. This may make her at higher risk of various impacts (Chapters 1 and 5) and thus in need of greater support.
- As an asylum seeker with no formal employment, Esmeralda is likely to struggle for money and basic goods and will probably be one of the many caregivers using food banks (Chapter 1).
- Esmeralda may struggle to find good employment once she has status, which will make it hard for her to juggle earning and care on an ongoing basis (Chapter 7).
- Depending on the country she is in, Esmeralda is likely to be excluded from income support as a caregiver because of her migration status, pushing her into poverty (Chapters 1 and 8).
- *Policies for Esmeralda: access to income support for asylum seekers, cultural education on racism and xenophobia, access to mental health support services, access to training and employment with flexibility to accommodate caring responsibilities*

Exercises for Small Groups

2) Investigating our own political context

In small groups, spend time online finding out what policies and support exists for carers/caregivers in your own country/state. Try to find at least 2 things. Discuss among yourselves the following questions:

- what did you find and what does it aim to achieve?
- do you think it sounds effective? what's good about it and what's flawed?
- who do you think would benefit most from what you've found?
- how does what you found relate to what you've learned from '*Who Cares*'?
- did anything surprise you in this process - for example, how easy/hard it was to find things, criteria that you weren't expecting, or things you thought would exist but don't?

After finding and discussing your materials, join the whole class and hear from each group in turn.



Overarching Essay Questions

These questions are designed to be appropriate for longer essays and pertain to themes throughout the book. You may also wish to adapt some of the chapter-specific questions into essay questions.

- Discuss the ways in which caregiving impacts people's lives - include at least two of the following factors: social, financial, romantic, physical, mental.
- To what extent has caregiving shaped women's lives historically and in what ways does this continue today?
- Can technology be an effective and/or comprehensive solution to our caring needs?
- Is care an issue of public or private concern? Make a case for your chosen option.
- The author argues that care should be understood as a 'species activity' not a 'sector'. How do these approaches differ and what does this mean for policy solutions?
- The work world is designed as if care did not exist. Discuss this assertion, including alternative arrangements.
- What is the role of government in relation to care? Include at least two of the following: money, workplace rights, urban space and architecture, technological principles.