



Care Companion Implementation Guide





Contents

1 Introduction	3
2 Shared Decision-Making	3
What is shared decision-making?	3
Why is shared decision-making important for people with serious health conditions?	4
What tools are available to support shared decision-making?	5
3 Care Companion Patient Decision Aid	5
What is the Care Companion?	5
Is it a legal document?	7
How do I use it?	7
Which version is best for my patient?	8
4 Key Steps for Implementation	9
Step 1 - Identify local decision-making needs	9
Step 2 - Decide if the Care Companion is right for your setting	9
Step 3 - Explore implementation barriers	10
Step 4 - Employ implementation strategies	12
Step 5 - Monitor use and outcomes	13
5 Supporting Resources	13
6 References	14

1 Introduction

This is a guide for healthcare professionals and teams who would like to implement the *Care Companion* in their workplace. Use this document to learn more about shared decision-making, the *Care Companion* patient decision aid, key steps involved in implementation, and supporting resources.

“Patients and families will be greatly supported by holding the *Care Companion* as they navigate the complex journey of progressive advanced disease and decision-making surrounding potential treatments to support their best quality of life. Starting with ‘Truth Telling’ often the most difficult part of the patient/family/clinician interaction, where ‘bad news’ is feared and communication needs to be on the patient’s terms, the *Care Companion* supports the individual’s values and choices. I have always valued ‘personhood’ as the most important aspect of caring for those at end of life and wish to endorse this very significant document, as it will improve shared decision-making for our patients, carers, and families.”

Associate Professor Carol Douglas - Medical Director, Queensland Palliative Medicine Training Program

2 Shared Decision-Making

What is shared decision-making?

Shared decision-making is a process where patients and clinicians make a health decision together (1). It involves:

- Discussing available treatment and care options
- Reviewing the benefits, risks, and unknowns of each option
- Considering the patient's values, preferences, and circumstances (1).

Current literature suggests that involving patients and carers in decision-making can improve satisfaction with care and leads to better quality decisions (2), especially for vulnerable patient populations who are likely to be at increased risk of poorer health outcomes (3).

Shared decision-making is a core component of value-based healthcare, which aims to improve the health outcomes that matter to patients relative to the resources or costs required (4). In Australia, over 10% of overall government economic activity is spent on health, with the demand increasingly rising (5). It is vital that these scarce resources are supporting valuable services that meaningfully improve patients’ and carers’ lives, in ways that matter most to them (4).

What are the benefits of shared decision-making for patients and carers?

- Enabling evidence and patient preferences to be incorporated
- Improved knowledge and perception of risk
- Improved patient-clinician communication
- Improved feeling informed and less decisional conflict (1).

What are the benefits of shared decision-making to healthcare professionals, teams, and organisations?

- Improved patient-clinician communication
- Improved patient engagement
- Improved patient satisfaction with care
- Improved delivery of person-centred care, which underpins the principles and expectations of the [National Safety and Quality Health Service \(NSQHS\) Standards](#) (1, 2, 6).

“I’m the expert on the disease, the prognosis, and the outcomes... and the patients are experts on themselves. We can’t have one without the other. We need to meet in the middle and go down a pathway together that is best for them.” – Anaesthetist


Why is shared decision-making important for people with serious health conditions?

Shared decision-making is a hallmark for good clinical practice and person-centered care (1). While it is applicable to most situations, it is particularly important when:

- There is uncertainty as to which treatment or care option is best for the patient
- The available treatment and care options have different benefits and risks
- The decision is likely to be influenced heavily by the patients’ values and preferences (1).

People diagnosed **with serious health conditions** often face complex, preference-sensitive decisions. That is, where there is no scientifically proven ‘best’ option and so the decision needs to be aligned with the persons values and preferences. This may include decisions about treatment that may prolong length of life, but reduce quality of life, or impact the ability to spend time at home. Shared decision-making is especially important for people with serious or life-limiting health conditions nearing the end of life, to support them in making informed choices in the context of prognostic uncertainty and reduced survival time (7).

Serious health conditions are those that carry a high risk of mortality and either negatively impacts a person’s daily function or quality of life, or excessively strains



their caregivers (8). Examples include advanced cancer, lung disease, liver disease, renal failure, neurological conditions, frailty, and many others.

What tools are available to support shared decision-making?

Patient decision aids are communication tools designed to facilitate shared decision-making between patients and their healthcare professional or team. They state the decision, describe the treatment and care options available, and prompt people to think about the options from a personal perspective. Patient decision aids may be pamphlets, videos, or web-based tools, and may be used before, during or after the clinical encounter (9).

A recent Cochrane review showed that when adults used decision aids, they had:

- Improved knowledge
- Improved understanding of the benefits, risks, and unknowns of treatment options
- Improved participation in shared decision-making
- Improved feeling informed and clear about what mattered most to them (9).

Despite these benefits, further research is needed to assess the impact of patient decision aids on costs and use of resources (9).


Knowledge exchange alone is not sufficient — shared decision-making needs to occur in a context where patients are enabled and supported to have a more active role (1).

3 Care Companion Patient Decision Aid

What is the Care Companion?

The *Care Companion* is a patient decision aid that facilitates shared decision-making for people with serious health conditions. It was co-designed by healthcare professionals and consumers in Queensland, to address a locally identified problem and driver of low value care at the end of life:

People with serious or life-limiting health conditions (and those involved in their care) may not receive the information and support they need to fully participate in shared decision-making about treatment and care that is right for them. – High Benefit Care at End-of-Life Working Group, 2021



The purpose of the *Care Companion* is to facilitate honest conversations between patients and their healthcare professional and guide decisions about treatment and care. It is made up of four key sections:

Truth Telling

- This section prompts the patient to consider whether they want to know more about their health condition, including how serious it is, and whether they want to be involved in decision-making.
- The responses provided can guide the conversation led by the healthcare professional.

Values & Preferences

- This section prompts the patient to consider what matters to them and how their values and preferences might influence decision-making.
- Additional requests or supports to enable decision-making can be noted here.

Decision-Making

- This section prompts the healthcare professional to outline the decision and provide balanced information about the benefits and risks of the available treatment and care options.
- The patient can then indicate how much the benefits and risks matter to them.

Next Steps

- This section prompts the patient to consider whether they understand the benefits and risks of each option, are clear about what matters to them, have received enough information and support, and if they feel sure about the best choice for them.
- The responses provided can guide any follow-on actions required.

The *Care Companion* is inspired by the Ottawa Personal Decision Guide and has been designed to be used flexibly. It may be introduced by healthcare professionals or patients, and used before, during and/or after the clinical encounter depending on the local need. Unlike patient decision aids that are specific to one type of decision, the *Care Companion* is a generic patient decision aid (also known as a decision guide), meaning that it can be used to guide almost any preference-sensitive decision.

“The *Care Companion* complements rather than replaces shared decision-making conversations.” – ICU Staff Specialist

Watch a short video explaining the *Care Companion* [here](#).

All resources are free to access, download or print [here](#).

Is it a legal document?

No, the *Care Companion* is not a legal document. Instead, it supports reaching a ‘good’ decision from a personal perspective.

The *Care Companion* is also different to [Advance Care Planning \(ACP\)](#) documents, which includes an *Enduring Power of Attorney*, *Advanced Health Care Directive*, *Statement of Choices*, or *Acute Resuscitation Plan*. These ACP documents record the decisions that a patient has made about the care they would or would not want in the future if they could not speak for themselves.

How do I use it?

Follow the steps below to use the *Care Companion*, noting that there will be other factors to consider depending on the local needs of patients, carers, and healthcare professionals.

Prepare

- **Ask** the patient if they would like to use the *Care Companion*, explaining what it is and how it can help. Ideally, it should be introduced at the time of diagnosis when people are actively seeking information and decisions need to be made.
- **Identify** the most appropriate healthcare professional to lead the conversation. Often, this will be the patient’s doctor or nurse practitioner. That is, the clinician who has the most knowledge of the patient’s health condition and the available treatment and care options available, including their benefits, risks, and unknowns.
- **Schedule** a suitable appointment to use the *Care Companion*. It may be useful to provide a copy to the patient in advance to allow time for reflection about the role they would like to play in decision-making, what is important to them, and who else they would like to include in the discussion. Remember, many patients rely on their carers, families, or trusted friends to support or lead decision-making.

‘We need to make an important decision about treatment for your health condition. I would like to give you some information, and understand what is important to you, so that we can make a good decision, together. The *Care Companion* is a tool that can help – would you like to give it a try?’

Complete

- **Before the clinical encounter** ensure that a copy of the *Care Companion* is available; either a printed or electronic version using a portable device such as an iPad or tablet. If the patient received a copy in advance, encourage them to bring it along and prompt them to share it with you.
- **During the clinical encounter** complete each section of the *Care Companion*. Use plain language to describe the decision and the benefits, risks, and unknowns of each option, helping patients to consider them from a personal perspective.

- *After the clinical encounter* encourage the patient to keep their *Care Companion* to reflect on the information provided and share with those close to them.

Some patients may need extra support from their healthcare professional to articulate their values, as this is not a commonly asked question in healthcare. Others may feel more comfortable reflecting on what matters to them with carers, family, or trusted friends prior to the clinical encounter.

Enact

- *Address* any follow-on actions identified.
- *Document* a short summary of the conversation and any decisions made in the patient's medical record and communicate with other members of the healthcare team as appropriate.

If the patient's condition changes or they have another decision to make, a new *Care Companion* can be completed or additional pages or resources can be accessed [here](#).

Which version is best for my patient?

There are three versions of the *Care Companion* – the full version, short version, and easy version. See below to consider which may be suitable for your patient.

- *The full version* may be used to support people with serious health conditions to have honest conversations with their healthcare team and make decisions about their treatment and care.
- *The short version* may be used if a decision needs to be made quickly, or a shorter version is preferred. It has been condensed into one double-sided A4 sheet though retains the key sections found in the full version.
- *The easy version* may be used if a shorter, simplified version is preferred. It has been designed using everyday words, short phrases, and clear sections. It should be completed during the clinical encounter, led by the healthcare professional or team, alongside the patient and their chosen support person.

Many patients want to know how serious their health condition is, including if it may limit or shorten their life. Patients often prefer to receive this information face-to-face, from a trusted healthcare professional (for example, a doctor who is known to them), together with written information in plain language (10).

4 Key Steps for Implementation

See below for the key steps involved in implementing the *Care Companion* within your setting. These steps are based on existing implementation resources from the Ottawa Hospital Research Institute (10), current literature, and learnings from local field testing.

Step 1 - Identify local decision-making needs

Consider the common health decisions that patients in your setting face when diagnosed with a serious health condition. It may be helpful to map the patient journey (Figure 1) or care pathway, noting when patients are referred, the timing of key appointments, when decisions need to be made, and who is involved in decision-making.

You may also consider gathering information from patients, carers, families, and all members of the healthcare team, to better understand patients' decision-making needs and challenges. This may be via informal conversations, surveys, review of local quality data or literature specific to your setting. Together, these findings will help to determine the local need, and whether implementation of a decision aid such as the *Care Companion* may be useful.

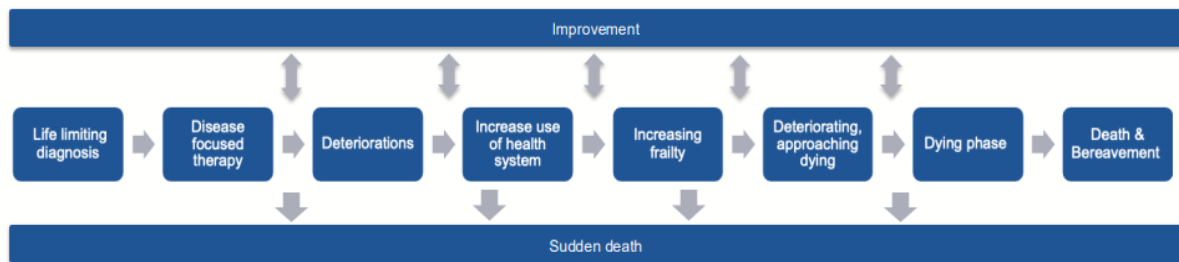


Figure 1. An example of a patient journey upon diagnosis of a life-limiting illness as developed by the High Benefit Care at End-of-Life Working Group 2021

People often have decisional needs when faced with decisions that have more than one option, uncertain outcomes, or known outcomes that people value differently (11).

Step 2 - Decide if the Care Companion is right for your setting

- Do you care for patients with serious health conditions who face difficult preference-sensitive health decisions?
- Do you want to facilitate early, honest conversations about your patient's health condition and what might happen in the future?
- Do you want to empower patients, carers, and families to fully participate in shared decision-making?

If so, the *Care Companion* may be right for your patients and healthcare team.

Examples of preference-sensitive health decisions may include commencement or withdrawal of treatment (i.e., chemotherapy, renal dialysis, placement of feeding tubes), treatment and care in the event of deterioration (i.e., admission to intensive care unit, transfer to hospital from a residential aged care facility), place of care toward the end of life (i.e., home versus palliative care unit) and many others.

Alternately, if you work in a setting where specific health decisions routinely need to be made (i.e., radiation or surgery for prostate cancer) you may wish to search for an existing high-quality decision aid via the [Ottawa Hospital Research Institute A to Z Inventory of Decision Aids](#).

Step 3 - Explore implementation barriers

Determine how you will use the *Care Companion* in your setting. Consider what barriers may present and develop tailored strategies as a healthcare team to overcome them. Be sure to capture the views of key people who will use or complete the *Care Companion*, including patients, carers, and all members of the healthcare team.

For example:

- Who are the key people that will use, introduce and/or complete the *Care Companion* in your setting?
Consider patients, carers, families, and all members of the healthcare team.
- What could get in the way of using the *Care Companion* in your setting?
Consider all possible barriers that may relate to patients, healthcare professionals, the environment, or resources. See Table 1 for more information.
- What strategies could be employed to make it easier to adopt the *Care Companion* in your setting?
Consider how its principles align with local standards and policies, which healthcare leaders will be important to involve in the implementation process, and explore ideas from patients, carers, families, and healthcare professionals as to how identified barriers may be overcome.

“Clinician motivation to use patient decision aids is driven through ownership.” – Nurse Practitioner.



Table 1. Identified barriers and strategies for using the *Care Companion* patient decision aid.

Barriers	Strategies
Time: Healthcare professionals are time poor	Consider, <ul style="list-style-type: none">• providing a copy of the <i>Care Companion</i> to the patient in advance of the clinical encounter, allowing time to complete the relevant sections in Truth Telling and Values and Preferences.• developing evidence-based ‘summary cards’ for common decisions, treatment options, and their benefits and risks, which healthcare professionals can easily access and use during the clinical encounter.• using the short version of the <i>Care Companion</i> to support quick decisions (where appropriate), or if it is more practical for use during the clinical encounter.
Overwhelm: Patient overwhelm or cognitive burden can make shared decision-making difficult	Consider, <ul style="list-style-type: none">• using the simplified version and tailoring communication, information, and timing of the conversation to their needs.• employing additional strategies to ensure equal opportunity for shared decision-making (i.e., using a paper version where preferred, drawings where useful, plain language, etc.)
Competing Priorities: Healthcare professionals forget to introduce or use it	Consider, <ul style="list-style-type: none">• generating awareness of the <i>Care Companion</i> and ownership among the entire healthcare team and integrating into existing workflows.• measuring outcomes that are linked to organisational values, so that healthcare professionals can easily see the improvements that have resulted from using the <i>Care Companion</i>.• empowering patients, carers and families to introduce the <i>Care Companion</i> by ensuring that resources are freely available to them in waiting rooms or online.
Feeling Unprepared: Healthcare professionals feel unprepared for shared decision-making	Consider, <ul style="list-style-type: none">• engaging with or providing local training – use this guide and accompanying resources to support your healthcare team.• seeking out additional training opportunities relating to shared decision-making, communication, and interpersonal skills.

Senior-Level Buy-in: Healthcare leaders are not involved in implementation planning

Consider,

- engaging with healthcare leaders, managers, and executives throughout implementation.
- securing senior-level buy-in by linking the *Care Companion* with organisational priorities such as shared decision-making and person centered-care.
- ensuring that healthcare leaders are part of the core team driving implementation forward.

Step 4 - Employ implementation strategies

Use the information gained in steps 1-3 to employ tailored implementation strategies, as guided by the local needs of patients, carers, families, and all members of the healthcare team. Additional strategies to support successful implementation of patient decision aids, as adapted to the *Care Companion*, are listed below.

Empower patients, carers, and families


- Power imbalances exist in some clinical encounters, with many patients believing they cannot participate in shared decision-making. When healthcare professionals make resources accessible, and prepare and prompt patients to use them, patients are more likely to feel that their contribution is valued. In turn, they are more likely to share their preferences, ask questions, and engage in shared decision-making (12).
- Empower patients to use the *Care Companion* by ensuring that copies are easily accessible in waiting rooms or online, prepare them to engage with it, and prompt them to share it with their healthcare professional during the clinical encounter.

Provide training for the healthcare team

- Healthcare professionals who receive training in shared decision-making have greater confidence in their skills and are better positioned to use decision aids in their practice (12).
- Use the resources featured within the [Care Companion Toolkit](#) to upskill the healthcare team, while promoting local training opportunities relating to shared decision-making, communication, and interpersonal skills.

Secure senior-level buy-in

- While it is important to engage the entire healthcare team to successfully implement decision aids in clinical practice, senior level buy-in is especially important for keeping the momentum going (12).
- Link the *Care Companion* with organisational priorities, values, and standards, and highlight how it will support your organisation in achieving them. Bring clinical leaders together who, alongside a clinical champion, can drive implementation forward by promoting resources, providing training, and evaluating outcomes.



The best strategies for implementation will be guided by the local needs of patients, carers, and healthcare professionals (10).

Step 5 - Monitor use and outcomes

Following implementation of the *Care Companion*, it is important to monitor its use and how effective it has been at improving locally determined outcomes.

To monitor use of the *Care Companion*, consider reviewing the number of patients who were eligible to receive it and whether they received it and engaged with it. Capture feedback from patients, carers, families, and healthcare professionals to understand how it was used, if any additional barriers were experienced, or if any questions arose.

There are various ways to monitor outcomes of decision aids such as the *Care Companion*. Some common measurement tools include:

- [Sure Test](#) – a short tool that screens for clinically significant decisional conflict
- [Decision Conflict Scale \(DCS\)](#) – a longer tool that measures the 5 dimensions of decision-making
- [Decision Regret Scale](#) – measures patient regret or remorse for the health decision made
- [Decision Support Analysis Tool \(DSAT-10\)](#) – evaluates the quality of decision support provided by healthcare professionals.

These findings can then be used to provide feedback to healthcare professionals, which will be important for sustained implementation. Healthcare teams will be more likely to embed the *Care Companion* into their routine clinical practice if there is clear evidence of improved patient outcomes.

To learn more, provide feedback, or share your experiences, please contact HIU@health.qld.gov.au.

5 Supporting Resources

The following resources may further support healthcare professionals and teams to engage in shared decision-making:

- [Shared decision making | Australian Commission on Safety and Quality in Health Care](#)
- [Patient Decision Aids Research Group - Ottawa Hospital Research Institute \(ohri.ca\)](#)
- [Communication and Shared Decision Making / Acute Care / Settings of Care / Health Professionals \(caresearch.com.au\)](#)
- [Shared Decision-Making | Bond University | Gold Coast, Queensland, Australia](#)
- [Shared decision making \(nsw.gov.au\)](#)

6 References

1. Hoffmann TC, Legare F, Simmons MB, McNamara K, McCaffery K, Trevena LJ, et al. Shared decision making: what do clinicians need to know and why should they bother? *Medical Journal of Australia*. 2014;201(1):35-9.
2. Australian Commission on Safety and Quality in Health Care. Shared decision making 2023 [Available from: <https://www.safetyandquality.gov.au/our-work/partnering-consumers/shared-decision-making>].
3. Durand M-A, Carpenter L, Dolan H, Bravo P, Mann M, Bunn F, et al. Do interventions designed to support shared decision-making reduce health inequalities? A systematic review and meta-analysis. *PloS one*. 2014;9(4):e94670.
4. World Economic Forum. Eliminating ineffective spending on global health through value-based healthcare 2023 [Available from: https://www.weforum.org/impact/accelerating-value-based-healthcare-globally/?gclid=EAIaIQobChMIhc3fm9vn_wlVAdZMAh1N-AnfEAAAYASAAEgIBHPD_BwE].
5. Australian Institute of Health and Welfare. Health expenditure Australia 2020-2021. 2022.
6. Australian Commission on Safety and Quality in Health Care. National Safety and Quality Health Service Standards. 2nd ed. – version 2. Sydney: ACSQHC; 2021.
7. Cardona-Morrell M, Benfatti-Olivato G, Jansen J, Turner RM, Fajardo-Pulido D, Hillman K. A systematic review of effectiveness of decision aids to assist older patients at the end of life. *Patient education and counseling*. 2017;100(3):425-35.
8. Kelley AS, Bollens-Lund E. Identifying the population with serious illness: the “denominator” challenge. *Journal of palliative medicine*. 2018;21(S2):S-7-S-16.
9. Stacey D, Lewis KB, Smith M, Carley M, Volk R, Douglas EE, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*. 2024;1(1):Cd001431.
10. Ottawa Hospital Research Institute. Implementation Toolkit 2022 [Available from: <https://decisionaid.ohri.ca/implement.html>].
11. Hoefel L, O’Connor AM, Lewis KB, Boland L, Sikora L, Hu J, et al. 20th Anniversary Update of the Ottawa Decision Support Framework Part 1: A Systematic Review of the Decisional Needs of People Making Health or Social Decisions. *Medical Decision Making*. 2020;40(5):555-81.
12. Joseph-Williams N, Abhyankar P, Boland L, Bravo P, Brenner AT, Brodney S, et al. What works in implementing patient decision aids in routine clinical settings? A rapid realist review and update from the international patient decision aid standards collaboration. *Medical Decision Making*. 2021;41(7):907-37.