

CANCER NURSES SOCIETY OF AUSTRALIA



It Takes a Village:

Coordinated Informal Care



The Reality of Informal Care





Informal care makes treatment possible.

When it fails, the consequences are clinical.



Missed transport can mean missed treatment.



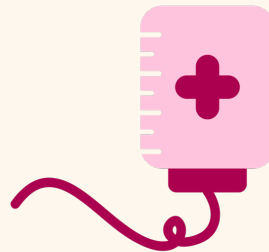
Poor nutrition compromises treatment and recovery.



Parenting responsibilities compromise rest, recovery and self-care.



Unmet household needs compromise safety at home.



Managing complex care alone increases risk.



Navigating cancer care alone compromises wellbeing, treatment and recovery.



The system already depends on informal care to function.

What it hasn't done is build mechanisms to activate it more effectively.



Our Existing Model







► J Geriatr Oncol. 2024 Nov;15(8):102079. doi: 10.1016/j.jgo.2024.102079. Epub 2024 Oct 15.

Support roles, carer burden, and decision-making preferences of carers of older adults with cancer

Wing Sze Lindsay Chan ¹, Vasi Naganathan ², Abby Fyfe ³, Alina Mahmood ⁴, Anne Warby ⁶, Duong Pham ⁷, Natalie Southi ⁷, Sarah Sutherland ⁸, Eir

► Support Care Cancer. 2022 Jun;30(6):4857-4865. doi: 10.1007/s00520-022-06857-2. Epub 2022 Feb 14.

Caring for someone with cancer in rural Australia

► Eur J Cancer Care (Engl). 2022 Apr 11;31(4):e13587. doi: [10.1111/ecc.13587](https://doi.org/10.1111/ecc.13587)

ks ⁵, Kristiaan J J Spronk ⁶, Chloe Fletcher ⁶,

The quality of life of regional and remote cancer caregivers in Australia

[Belinda C Goodwin](#) ^{1,2,✉}, [Fiona Crawford-Williams](#) ^{1,2,3}, [Michael Ireland](#) ^{2,4}, [Sonja March](#) ^{2,4}, [Suzanne K Chambers](#) ^{5,6,7}, [Joanne F Aitken](#) ^{1,2,8,9}, [Jeff Dunn](#) ^{1,2,5,10,11}

► Cancer. 2025 Jul 15;131(14):e35970. doi: 10.1002/cncr.35970.

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► BMJ Open. 2020 Jan 19;10(1):e032361. doi: [10.1136/bmjopen-2019-032361](https://doi.org/10.1136/bmjopen-2019-032361)

Cancer caregivers' experiences of prognosis in Australia: a qualitative interview study

[Sophie Lewis](#) ^{1,✉}, [Alex Broom](#) ², [Katherine Kenny](#) ², [Emma Kirby](#) ¹

economic burden of cancer caring

[Imu Mudiyanse](#) ¹, [Anna Ugalde](#) ², [Jennifer J Watts](#) ¹, [Geetha Thomas](#) ², [Neha Das](#) ¹, [Andrew Lyall](#) ³, [Natalie Winter](#) ², [Siobhán McCaffrey](#) ¹, [Victoria White](#) ⁴, [Patricia M Livingston](#) ^{2 5}



And so we get this...

- + 59,100 cancer carers annually
- + 28.6 hours per week
- + \$3.6 billion in unpaid care
- + \$60,853 lost income per carer, per annum
- + Women carry 66% of care hours
- + Report higher distress levels than patients







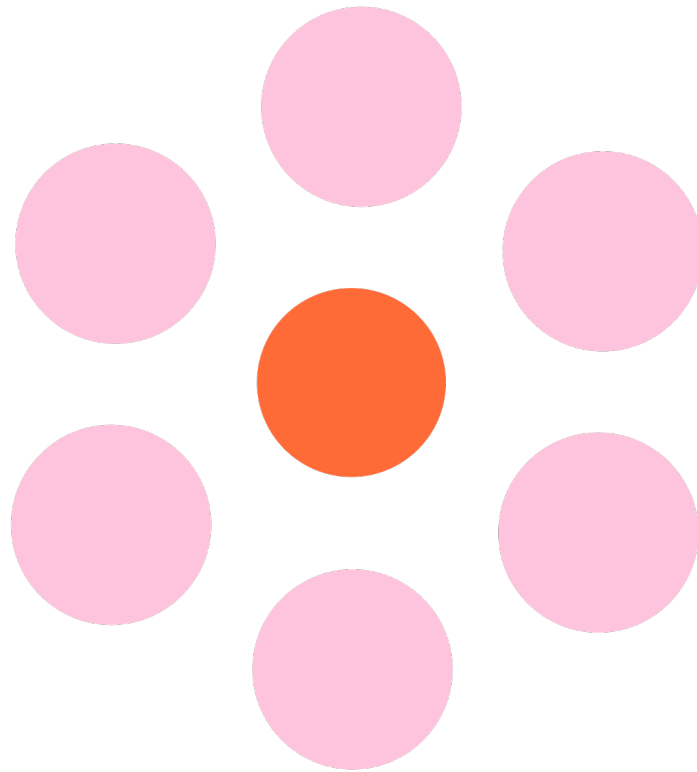




Let's stop leaving one of the most
powerful resources in cancer care
untapped.

Coordinated Informal Care







Coordinated Informal Care

- ✦ Provided by community
- ✦ Shared, sustainable, coordinated
- ✦ Targeted to patient-identified needs
- ✦ Technology-enabled
- ✦ Includes guidance to build caring confidence

Outcomes of Coordinated Informal Care



- ♥ For Patients
- ♥ For Primary Carers
- ♥ For Health Services
- ♥ For Communities



Why Coordinated Informal Care Doesn't Just Happen



The Gap Between Intention and Action



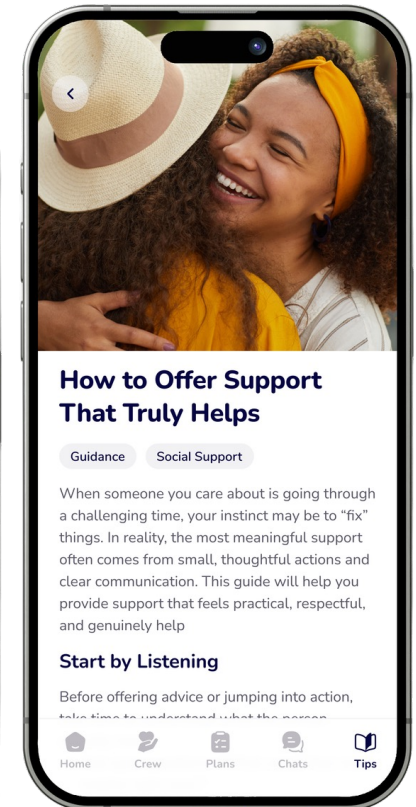
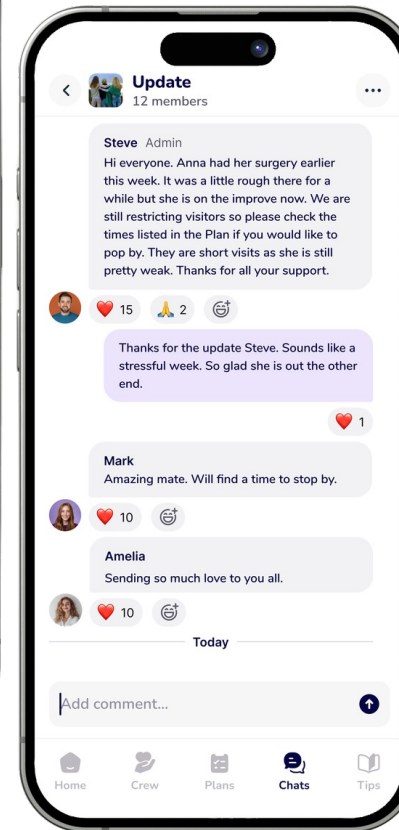
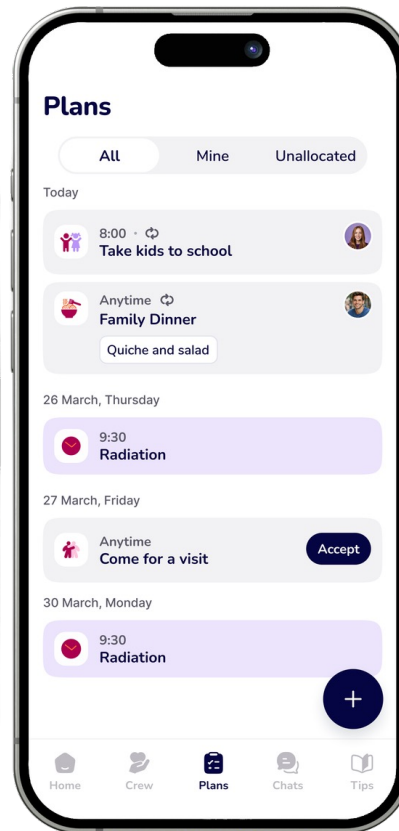
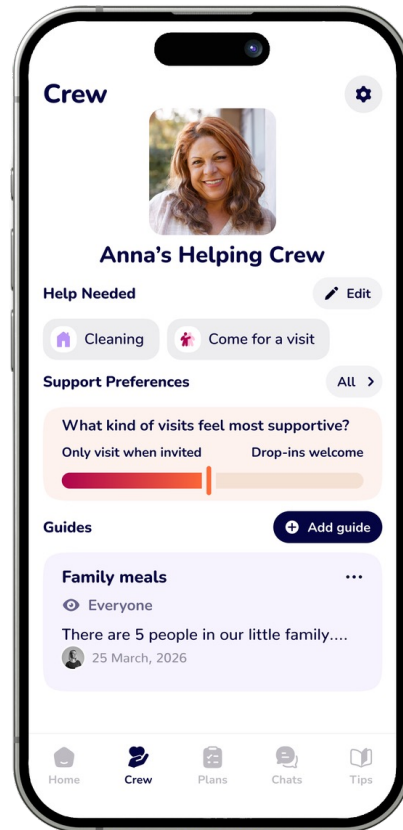
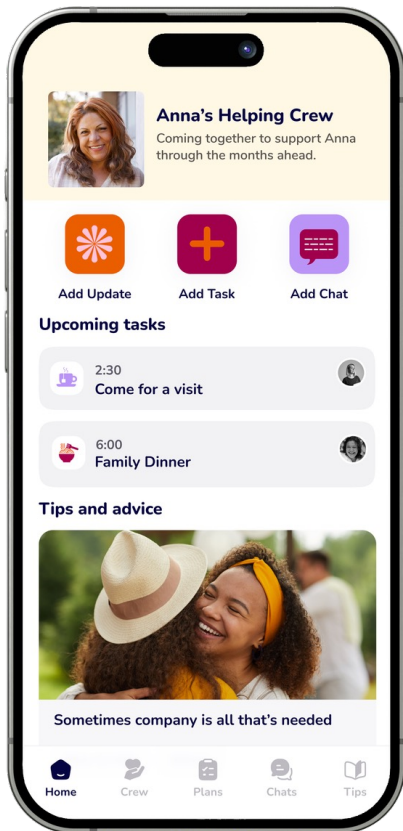
Why "Let me know if you need anything" is a thoroughly unhelpful thing to say...



The Gather My Crew App



Turning Goodwill Into Practical Support



Designing For The Barriers



Technology removes the awkwardness of asking for help.



Guided onboarding helps people identify what support is needed.



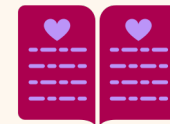
Support preferences help navigate difficult conversations early.



The Plan turns offers of help into practical action.



Chat keeps the network informed and reduces repeated updates.



Tips provide trusted guidance from leading support organisations.

When Support Is Coordinated...



~100,000 users
~480,000 hours

- ✓ Meals cooked and delivered... for months
- ✓ Social visits rostered
- ✓ Lawns mowed, dogs walked, bins taken out
- ✓ Transport to infusions, surgery, appointments
- ✓ School pick-ups, childcare, sports runs
- ✓ Overnight stays after surgery

300% increase in access to informal care



The Clinical Role: Embedding Coordinated Care





Who is **best placed** to take on this challenge?

Change The Conversation



“Do You Have Support At Home?”

- ☀ Almost always asked.
- ☀ Almost never tells the full story.

Change the question. Change the model.

When To Ask...



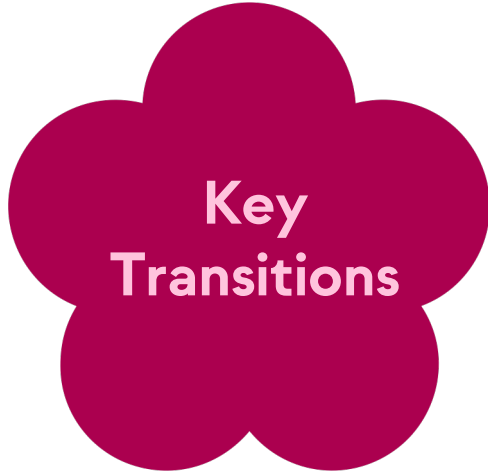
As early as possible... and then again.... and again...



Diagnosis



**Before
Treatment
Begins**



**Key
Transitions**



Because it does take a village...

And every one of you has the power to help build one.



Panel Discussion



Meet Our Panelists



Lauren

Primary carer for her
husband

Irina

Coordinator of a
support crew

Jade

Nurse Educator at
Icon Cancer Centre

Dan

Shares his perspective
as a cancer patient

