

NSW Health

Recognition And Support For Carers

Key Directions

**2023-27**

**Consultation Draft**

## Abbreviations

* **District** - Local Health District
* **eMR** - Electronic Medical Records
* **EtHE** - Elevating the Human Experience
* **LGBTIQ+** - lesbian, gay, bisexual, transgender and gender diverse, intersex, queer, and other diverse sexualities and genders
* **The Ministry** – the NSW Ministry of Health
* **Network** – Specialty Health Network
* **NSQHS** **Standards** – National Safety and Quality Health Service Standards
* **PAS** – Patient Administration System

# Background

## Who are Carers?

A carer is someone who provides ongoing, unpaid personal care, support and assistance to another person who needs help due to disability, a medical condition, a mental illness or being frail and aged. The role of a carer is defined in the NSW *Carers (Recognition) Act 2010.*

Caring may involve a few hours assistance per week through to sustained full-time care. It may also involve balancing full or part time work with caring responsibilities. Carers provide assistance with activities such as showering or dressing, mobility, transport, social and emotional support, communication, meal preparation, domestic assistance, medication management, financial management, and other aspects of the person’s daily life. Many carers may not see themselves as a carer or may not use the word ‘carer’ to describe themselves.

In the context of this policy, a person is not a carer if they provide care as part of paid employment, formal volunteering or education. A carer receiving Carer Allowance or similar payments is still considered to be providing unpaid care.

## Carers and NSW Health

Health services are used by carers and the people they care for. Involving a carer as a partner in care both benefits health staff and improves outcomes for patients. Within health services, carers can often provide unique insights into a patient’s health. Carers can assist in communicating complex information to patients, support patients with activities of daily living and facilitate patient flow throughout the health system, as well as providing valuable reassurance during a patient’s treatment.

Research has shown that carers experience lower health and wellbeing outcomes than the general population.[[1]](#footnote-1) Carers have a significantly higher incidence of chronic health conditions, with carers indicating that they often have little time to prioritise their own health. Caring often also has a significant impact on carers’ mental health. The NSW Carers Charter states that ‘Carers should be supported to enjoy optimum health and wellbeing’, and NSW Health plays a pivotal role in enabling this to occur. In seeking to achieve this goal, NSW Health also supports its employees who combine caring responsibilities and work.

## The purpose of this document

The NSW Health Recognition and Support for Carers: Key Directions 2023-2027 (the Key Directions) is designed to provide a framework for NSW Health’s response to the needs of carers across the NSW public health system. It aims to provide a context for planning local health district, specialty health network and state-wide activities. The document also highlights areas for system growth.

The attached Statewide Actions will highlight some state-wide activity to support carers for the first year of the Key Directions. This will be updated and reviewed each year.

This document builds on the NSW Health Recognition and Support for Carers Key Directions 2018-2020. This updated document complements and is supported by policy and legislation, as highlighted below, and aims to work with and expand on the broader NSW Health approach.

# Policy Context

## The NSW *Carers (Recognition) Act 2010*

[The NSW *Carers (Recognition) Act 2010*](https://legislation.nsw.gov.au/view/whole/html/inforce/current/act-2010-020) (the Act)*,* which includes the NSW Carers Charter,formally recognises the significant economic and social contribution of carers. Under the Act, Public sector agencies, including all NSW Health agencies, must embed the principles of the NSW Carers Charter in their work. This includes:

* acknowledging carers’ unique knowledge and experience
* supporting carers’ wellbeing
* recognising the diversity of carers’ needs, especially noting the needs of Aboriginal and Torres Strait Islander carers and young carers
* involving carers as partners in care.

NSW Health must also engage and consult with carers, or organisations that represent carers, on matters that impact them, and ensure that human resource policies consider carers’ needs.

The Key Directions outlines how NSW Health agencies can demonstrate the requirements of the NSW Carers Charter in a health context. NSW Health must report on compliance with the Act in each reporting period.

## Carers Strategy

The [NSW Carers Strategy: Caring in NSW 2020-2030](https://www.dcj.nsw.gov.au/community-inclusion/carers/nsw-carers-strategy.html) provides a framework for the whole of our community, including service providers, government and private businesses, to improve outcomes for carers and their families.

The strategy commits to four priorities:

1. Carers have better access to information, services and supports
2. Carers will be recognised, respected and empowered
3. Carers have improved financial wellbeing and economic opportunities
4. Carers have better health and wellbeing

The Key Directions outlines NSW Health’s response to achieve the priorities of the NSW Carers Strategy, recognising, respecting and empowering carers as they interface with NSW Health. It also brings a focus to NSW Health’s role in improving carers’ health and wellbeing.

NSW Health has committed to several actions in the [NSW Carers Strategy Action Plan 2023-2024](https://dcj.nsw.gov.au/documents/community-inclusion/carers/nsw-carers-strategy/nsw-carers-strategy-2nd-action-plan-2023-2024.pdf).

## Future Health

[Future Health](https://www.health.nsw.gov.au/about/nswhealth/Pages/future-health.aspx) is a roadmap for how NSW Health meets the increasing health demands and needs of our community over the coming decade. It aims to deliver on our vision for a sustainable health system that delivers outcomes that matter most to patients and the community, is personalised, invests in wellness and is digitally enabled. Implementing the Key Directions will help to meet several outcomes of Future Health:

* Supporting carers and working to measure experiences and outcomes will mean that “Patients and carers have positive experiences and outcomes that matter” (Outcome 1).
* Looking after carers’ wellbeing also helps ensure that “People are healthy and well” (Outcome 3).
* Providing support for NSW Health staff who are carers will help make sure that “our staff are engaged and well supported” (Outcome 4).

Caring for carers is fundamental to meeting the strategic outcomes outlined in Future Health and a necessary part of meeting Future Health’s person-centred approach to care.

## Elevating the Human Experience

Engaging and supporting carers is a necessary part of human-centred care. [Elevating the Human Experience – Our Guide to Action](https://www.health.nsw.gov.au/patients/experience/Pages/action.aspx) outlines what the NSW health system can do together, in partnership with patients, families and carers to consistently create positive, personalised experiences.

Elevating the Human Experience advocates and promotes that working in partnership with carers is an important policy objective as well as a key principle in understanding human-centred care. It also notes evidence suggesting that many carers are not receiving the support they need.

## [National Safety and Quality Health Service Standards (NSQHS)](https://www.safetyandquality.gov.au/)

Actions to better support and engage with carers will assist districts in fulfilling accreditation requirements under the NSQHS.

This includes opportunities to build evidence to demonstrate compliance with Standards, especially Clinical Governance, Partnering with Consumers, Comprehensive Care, and Communicating for Safety. Further information is available at [www.safetyandquality.gov.au](http://www.safetyandquality.gov.au/).

# Aim

The aim of the Key Directions is that carers feel valued, respected, engaged and supported in the NSW public health system.

# Key Directions

## 1. NSW Health will recognise, respect and empower carers as partners in patients’ care

NSW Health organisations can demonstrate this by:

* Identifying a patient’s carer(s) at admission and recording this in the eMR/PAS systems, following IB2019\_031 [Identifying the Carer at Patient Registration](https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=IB2019_031)
* Including carers in a patient’s care where they wish to be included, including providing hands‑on care
* Maintaining buildings, rooms, spaces and environments that allow a carer to attend to the person they care for
* Facilitating visitation wherever possible
* Notifying carers about changes in a patient’s condition or treatment, and providing clinical information to the carer, where appropriate
* Working with carers when planning a patient’s discharge and subsequent treatment, providing the carer with appropriate information, support and follow-up care
* Addressing carers’ own needs in addition to those of the person they care for
* Creating an environment where carers will feel safe to ask for help and support and safe to provide feedback
* Referring carers to appropriate information and support services, including [Carer Gateway](https://www.carergateway.gov.au/)
* Providing referral to bereavement counselling and support for carers where the person they are caring for dies

## 2. NSW Health will support patients who are carers to have better health and wellbeing

NSW Health organisations can demonstrate this by:

* Identifying a patient’s carer(s) at admission and recording this in the eMR/PAS systems, following IB2019\_031 [Identifying the Carer at Patient Registration](https://www1.health.nsw.gov.au/pds/Pages/doc.aspx?dn=IB2019_031)
* Supporting patients who are carers to find appropriate supports for the person they care for while attending a NSW Health service
* Creating an environment where patients who are carers will feel safe to ask for help and support, and to provide feedback
* Considering a patient’s needs as a carer, especially when planning for discharge
* Providing appropriate information, resources and follow-up support, including referring to Carer Gateway and other appropriate services

## 3. NSW Health will support its employees who are carers

NSW Health organisations can demonstrate this by:

* Promoting support for carers so that NSW Health employees can identify themselves as carers
* Providing information so that NSW Health employees who are carers know and understand their rights and available supports
* Building the capacity of NSW Health managers and executives to support carers, ensuring they understand the benefits of doing so and promoting the NSW Carers Charter
* Promoting and supporting flexible working and other workforce policies that support carers in their role
* Providing information on Carer Gateway where appropriate, and on other available supports

## 4. The NSW Health system will enable support for carers

NSW Health organisations can demonstrate this by:

* Supporting the Carers Program in each district or network
* Developing easily accessible resources that can be used to support carers
* Engaging carers meaningfully so that their views are included in assessing, planning, delivering and reviewing services, policies and other documents, and implementing approaches for doing so
* Developing and implementing systems to collect and use data to understand, address and respond to carers’ needs
* Promoting the NSW Carers Charter to employees and developing capacity to act in accordance with the Charter
* Developing or promoting access to relevant education and training
* Ensuring that NSW Health employees and volunteers are aware of the varied needs of diverse groups of carers, such as Aboriginal and Torres Strait Islander, multicultural, regional, rural and remote, LGBTQI+ and young carers, as well as how caring needs differ with different conditions
* Raising awareness of carers by supporting National Carers Week and other relevant events and promoting carers wherever possible
* Using the word ‘carer’ correctly and consistently across NSW Health policies and procedures, following the definition in the Act
* Building relationships between areas of NSW Health and with broader system stakeholders, such as Department of Communities and Justice, Carer Gateway and Carers NSW

# Implementation

The responsibility to engage with carers lies with all levels of the NSW Health system and all NSW Health agencies. In addition, collaboration and partnership with carers, government and non-government organisations is encouraged to promote a more inclusive health system and enduring outcomes for carers.

## Role of local health districts and specialty health networks

The Key Directions is designed to allow flexibility for local approaches. Local actions and programs to engage and support carers should embody the principles set out in the directions. Support for carers should occur at all levels of the district or network, from clinical care provision to policy and program development.

A local Carers Program was established in each district and network to enhance the responsiveness of the health system to the needs of carers. The Carers Programs will guide work in this area, aiming to coordinate work and implement these principles. However, support for carers is the responsibility of the whole NSW Health system, not the Carers Programs only.

The Carers Programs will vary according to the needs of each district and network. However, as a minimum, a Carers Program will:

* Build the capability of staff across the district or network to identify, engage and work with a diverse range of carers
* Promote carers’ interests, including in the development of policies, programs and information
* Make information, resources and supports available for carers
* Develop processes and information for enabling engagement with carers
* Support carers who are employees of that district or network
* Engage with state-wide work as needed, advising on local initiatives and raising any issues of concern

In addition to building district capacity, Carers Programs are also encouraged to consider providing direct support for carers where capacity allows.

The Carers Program Network, made up of the Carers Program managers in each district or network, will meet regularly to enable the sharing of ideas across NSW. These meetings will also provide an opportunity to showcase best practice and to raise emerging issues or opportunities. The Carers Program Network will be led by members and supported by the Ministry.

Districts and networks will be expected to provide regular reporting to the Ministry on how the Key Directions have been put into action throughout the district. This includes the Carers Program and wider district or network activity. Support for the Carers Program allows districts and networks to show their commitment to meeting the requirements of the Act and the NSW Carers Charter. Districts and networks are also expected to raise any emerging systemic issues with the Ministry.

## Role of the Ministry of Health

The Ministry will provide support to coordinate work around carers across NSW. This includes consideration of what systems and processes are needed to allow for better reporting, monitoring and governance across the state.

The Ministry aims to connect other state-wide programs of NSW Health that directly impact carers, including human experience, workforce, aged care, disability, priority populations and Aboriginal health, as well as the NSW Mental Health Carers Program and NSW Health Pillars. The Ministry will also foster connections with other NSW and Australian Government stakeholders, including Carers NSW, Department of Communities and Justice, and Carer Gateway.

In addition, the Ministry will continue to administer the Family and Carer Mental Health Program to support carers of people with a mental illness.

# Reporting, monitoring and governance

Wherever possible, carers projects and initiatives should be supported by evidence. Evaluation and monitoring should be considered in the design of carers services and projects. NSW Health agencies should evaluate the impact of projects and initiatives to support the delivery of services.

At a state-wide level, work under the Key Directions will focus on improving collection and interpretation of relevant data to understand the prevalence, composition and experience of carers in the NSW Health system, as well as activity to provide carer support. This will allow the development of data-driven approaches to monitoring current work and understanding future priorities.

The Ministry’s Health and Social Policy Branch will coordinate annual reporting against the Key Directions, and will publish information in the NSW Health Annual Report, as required by the Act. Through this, the Ministry will collect examples of best practice initiatives from each district and network. Reporting will also be provided to the Department of Communities and Justice, as required under the NSW Carers Strategy.

In addition, a focus of the implementation of the Key Directions will be to develop better state-wide approaches to elevate and include the carer voice across the system. Acknowledging the excellent work that is underway locally, this may involve coordination of the many local carer engagement groups already in place across NSW, as well as greater integration with peak bodies such as Carers NSW. The Ministry will also consider the role of carers in existing governance structures.

# Statewide Actions

This intends to capture state-wide actions only – it is not intended to be an action plan for all of NSW Health. Districts and networks should use the Key Directions in developing their local approach.

Actions in the plan below are intended to be completed or significantly underway in the first year of the Key Directions. This Action Plan will be updated each year to maintain its relevance.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Program/Project** | **Relevant Directions** | **Benefits** | **Responsible** | **Indicators of success** |
| **Maintain a Carer Support Program in each Local Health District** | 1, 2, 3, 4 | The Carer Support Program will provide professional support for carers, increase access by carers to a range of services, facilitate communication between carers and health professionals and add to the support services for carers in local communities. | All districts and networks, Ministry of Health | * Each district and network maintains a Carers Support Program that addresses the Directions in this document
* The Carers Program Managers Network meets regularly to share ideas, developments and issues
 |
| **Facilitate the NSW Health Carers Program Network** | 4 | The Carers Program Network is an opportunity to network, discuss priorities and work arising, showcase best practice and to raise emerging issues or opportunities. This includes regular meetings as well as the face-to-face annual Statewide Workshop. | Districts and networks, NSW Ministry of Health | * Regular meetings held
* Statewide Workshop held
 |
| **Maintain the Family and Carer Mental Health Program** | 1 | Working with people with a mental illness and supporting their families and carers is pivotal to achieving strong outcomes in mental health care. The program is delivered across 15 districts in partnership with five community managed organisations (CMOs) and Justice Health and Forensic Mental Health Network. | Ministry of Health - Mental Health Branch | * Districts and the Justice Health & Forensic Mental Health Network enhances the skills of mental health service staff to work with families and carers as partners in care
* CMOs provide training and education, one to one support, group support and advocacy services for families and carers of people with a mental illness
 |
| **Improve data collection and interpretation** | 4 | Better data will provide an evidence base for ongoing decisions around carers programs. Strengthening data collection will help raise the profile of carers. | Ministry of Health, working with districts and networks | * Sources of data around carers are known and understood
* Data collected through eMR and PAS is available and used Systems are in place to gather and analyse carer feedback
 |
| **Implement the Family and Carer Mental Health Program evaluation recommendations** | 1 | An evaluation of the Program was completed between June 2020 and December 2021. The evaluation found significant activity and positive outcomes. It also identified opportunities to enhance the Program. | Ministry of Health – Mental Health Branch | * Implementation of evaluation recommendations
 |
| **Obtain Carers + Employers accreditation for the Ministry of Health** | 3, 4 | Obtaining accreditation with this nationally recognised accreditation program will show that the Ministry values and supports its employees who are carers. The program will provide a platform for promotion of carers matters to NSW Health staff, as well as providing opportunities to provide support to staff carers. Districts and networks will also be encouraged to obtain accreditation. | Ministry of Health – Health and Social Policy Branch and Workforce Planning and Talent Development branch | * Level 1 accreditation received
 |
| **Promote Carers Week** | 1, 2, 3, 4 | Carers Week activities will raise the profile of carers across NSW Health’s work. | Ministry of Health, districts and networks |  |
| **Provide NSW Health information and resources to meet carers’ needs** | 1, 2 | This work aims to identify and fill any identified gaps in state-wide NSW Health resources to ensure that consistent resources are provided across the state. There will be a focus on priority populations such as CALD communities. | Ministry of Health | * Survey of available resources completed
* Gaps identified
* Plan in place to address gaps
 |

1. Cf. https://www.carersnsw.org.au/about-caring/impacts-of-caring [↑](#footnote-ref-1)