

NSW HEALTH
RECOGNITION AND SUPPORT FOR CARERS
KEY DIRECTIONS

2018 - 2020

ABBREVIATIONS

ABS	Australian Bureau of Statistics
ACI	Agency for Clinical Innovation
BHI	Bureau of Health Information
CEC	Clinical Excellence Commission
CPH	Centre for Population Health
ED	Emergency Department
FACS	Department of Family and Community Services
HETI	Health Education and Training Institute
HSPB	Health and Social Policy Branch
JH&FMHN	Justice Health and Forensic Mental Health Network
LHD	Local Health District
LGBTI	Lesbian, Gay, Bisexual, Transgender, Intersex
MoH	Ministry of Health
MHB	Mental Health Branch
NDIS	National Disability Insurance Scheme
PAS	Patient Administration System
SHN	Specialty Health Network
WR	Workplace Relations

RECOGNITION AND SUPPORT FOR CARERS: KEY DIRECTIONS 2018 – 2020

Carers provide ongoing unpaid* support to family members or friends who need help because of disability, terminal, chronic or mental illness or ageing. Supporting carers is the responsibility of all levels of Government and the community as a whole.

The NSW Health Recognition and Support for Carers: Key Directions 2018-2020 (the Key Directions) is designed to provide system-wide guidance on responding to the needs of carers across the NSW public health system.

Development of the Key Directions also fulfils NSW Health's obligations under the *NSW Carers (Recognition) Act 2010* which requires public sector agencies, including NSW Health, to recognise and value carers and ensure carers are consulted on policy matters that impact on them.

Aligning with the requirements of the *Carer (Recognition) Act*, under the Key Directions NSW Health will:

- Inform and guide its employees to recognise and support carers
- Value and engage with carers as partners in care
- Support employees who have caring responsibilities.

Actions developed by NSW Health organisations to implement the directions outlined in this document should be underpinned by the guiding principles of:

- **Inclusion:** the work undertaken to respond to the needs of carers acknowledges and respects the diversity of all carers including Aboriginal people, multicultural communities, refugees, lesbian, gay, bisexual, transgender, intersex, and young carers
- **Collaboration:** the expertise of carers is valued and used to achieve better and enduring change for carers
- **Evidence:** to support the delivery of services informed by good practice actions are monitored and evaluated.

System-wide consultation, the *NSW Carers (Recognition) Act*, and the NSW Carers Strategy 2014-2019 informed the development of this document.

NSW Health will work closely with the Department of Family and Community Services (FACS) and Carers NSW as key partners in the delivery of activities and projects it has committed to deliver under the NSW Carers Strategy 2014-2019.

*Receiving a government benefit or allowance for providing care to a family member does not invalidate a person as being a carer.

SNAPSHOT OF CARERS IN NSW

Carers are as diverse as the rest of the community and it is important that this diversity is recognised and acknowledged. Carers are also our colleagues in NSW Health and may need to be supported with the flexibility to balance work and caring responsibilities.

Carers play a critical role in our community by supporting family and friends. It is estimated it would cost over \$40 billion to replace the hours of care provided each year.

According to the Carers NSW 2016 Carer Survey carers' self-reported wellbeing continues to be significantly lower than the general Australian population. Most carers not only require health services and specific supports for the person for whom they care, but also for themselves.

All Carers

- Across NSW there are approximately **905,000** carers or **11.9%** of population
- Over **290,000** people are primary carers or **3.8%** of population (1)
- Around **618,000** carers are female or **8.1%** of population, with the majority aged between 25 and 64 years

Aboriginal carers

- Over **14,000** Aboriginal people provide assistance and support to family members and friends (2)

Carers with a disability

- Nearly **271,000** carers had a disability, with **6.5%** having profound/severe disability.

Young carers

- Around **71,000** of all carers are aged less than 25 years

Carers in the labour force

- Participation of carers was **55%** compared to **69%** of non-carers
- **59%** of employed carers worked full time compared to **68%** of non-carers
- Over **330,000** carers were unemployed and seeking full-time or part-time work

Source: Australian Bureau of Statistics (2015). Survey of Disability, Ageing and Carers

- (1) A primary carer is someone who provides the most informal assistance to a person with disability with one or more of the core activities of mobility, self-care and communication - Australian Bureau of Statistics, 4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2015
- (2) www.carersnsw.org.au/how-we-help/support/aboriginal/

KEY DIRECTIONS OVERVIEW

Vision

NSW Health and its employees recognise the important role of carers and respond to their needs, so that carers feel valued, respected, engaged and supported in the NSW public health system.

KEY DIRECTION 1

NSW Health will inform and guide its employees to recognise and support carers

KEY DIRECTION 2

NSW Health employees will value and engage with carers as partners in care

KEY DIRECTION 3

NSW Health will support employees who have caring responsibilities

ACTIONS

1.1 Promote the Act and NSW Carers Charter principles so that NSW Health and its employees understand and act on these

1.2 Engage carers in committees and working groups so they can influence issues and decisions that affect them

1.3 Support National Carers Week, and deliver activities that increase awareness of diverse groups of carers

1.4 Ensure employees and carers have access to resources with helpful information about support services, especially for those new to caring

1.5 Include the needs of carers when developing or reviewing policies, guidelines or documents that impact on them

1.6 Review and update the Health Education and Training Institute Partnering with Carers eLearning module

2.1 Complete scoping of changes to the NSW Health Patient Administration System to record at registration if a patient has a carer or not

2.2 Ensure meaningful engagement with carers so that their views and needs are included in the assessment, planning, delivery and review of services

2.3 Fund NGOs to deliver the NSW Family and Carer Mental Health Program, and Dementia Australia NSW to deliver dementia carers support groups

2.4 Increase carers' participation in the Get Healthy Information and Coaching Service and Stepping On falls prevention program

3.1 Access surveys and data sources to analyse the proportion and location of employees in NSW Health with caring responsibilities, to target efforts

3.2 Develop an information pack for employees with a caring responsibility, to outline NSW Health's support for their role

3.3 Engage employees with caring responsibilities in the development of policies, guidelines and other documents that impact on them

3.4 Create flexible working guidelines for management teams to effectively support to employees with caring responsibilities

3.5 Promote policies covering leave matters and flexible work practices to employees

Guiding principles

Inclusion → the diversity of carers including Aboriginal people, multicultural communities, refugees, lesbian, gay, bisexual, transgender, intersex, and young carers, is acknowledged, respected and placed at the centre when developing and implementing actions for carers

Collaboration → collaboration and partnership with carers, government and non-government organisations is key to achieving a more inclusive health system and better and enduring outcomes for carers

Evidence → NSW Health organisations should use tools to evaluate the impact of projects and initiatives to support the delivery of services informed by good practice

ACTION PLAN

Key Direction One					
NSW Health will inform and guide its employees to recognise and support carers					
Action	Benefits	Key responsibility	Partners	Indicators of success	Timeframe
1.1 Promote the Act and NSW Carers Charter principles so that NSW Health and its employees understand and act on these	NSW Health employees understand the Act and reflect the Charter principles in their daily activities. In embedding a carer culture, NSW Health will improve carers' experiences of the public health system, either as patients or as carers, and influence behaviours that assist them to improve their health and wellbeing.	All NSW Health	MoH	Education sessions, presentations and promotion is delivered based on evidence of good practice and evaluation of successful approaches.	Each year
1.2 Engage carers in committees and working groups so they can influence issues and decisions that affect them		All NSW Health	MoH	NSW Health organisations can provide examples of how carers' engagement in committees and working groups has led to improved outcomes for this group.	Each year
1.3 Support National Carers Week, and deliver activities that increase awareness of diverse groups of carers		LHDs/SHNs /MoH	FACS Carers NSW	National Carers Week promoted and celebrated, including activities to raise awareness of carers from diverse groups.	Each year
1.4 Ensure employees and carers have access to resources with helpful information about support services, especially for those new to caring	Information packages for employees and carers, especially those who are new to caring, are available to provide a consistent message across NSW. Resources can be tailored to reflect local demographics and serve as a tool for employees to guide carers towards support services in and outside the public health system. Resources are kept up to date reflecting relevant changes to support services including developments on national reforms that impact on carers.	LHDs/SHNs	MoH	Resources are up to date, usefully organised, accessible to multicultural communities and people with disability, and promoted through the NSW Health intranet and internet sites. Resources have been co-designed with carers and/or carer organisations.	Resources to be updated or developed confirmed at the start of each year
1.5 Include the needs of carers when developing or reviewing policies, guidelines or documents that impact on them		All NSW Health	MoH	NSW Health organisations can provide evidence of consultation with carers in the development of policies, guidelines or documents, and how this has supported improved outcomes for this group.	Each year
1.6 Review and update the Health Education and Training Institute Partnering with Carers eLearning module		Carers' needs and views are taken into account and incorporated in documents that impact on them.	HETI	LHDs/SHNs /MoH LHDs/SHNs	eLearning module reviewed and updated. eLearning module promoted resulting in an increasing number of staff completing the training each year.

Key Direction Two <i>NSW Health employees will value and engage with carers as partners in care</i>					
Action	Benefits	Key responsibility	Partners	Indicators of success	Timeframe
2.1 Complete scoping of changes to the NSW Health Patient Administration System to record at registration if a patient has a carer or not	Identifying the carer as a person to contact would: <ul style="list-style-type: none"> • Foster communication between NSW Health staff and carers • Support clinicians to involve the patient and their carer in discussions, coordination and planning of care and discharge from hospital • Facilitate targeted support for carers by Carer Support Services, clinicians and allied health staff. 	HSPB-MoH	eHealth NSW LHDs/SHNs State forms Management Committee	Changes made to NSW Health PAS to identify if a patients has a carer or is a carer at registration	March 2019
2.2 Ensure meaningful engagement with carers so that their views and needs are included in the assessment, planning, delivery and review of services	NSW Health employees work in partnership with carers in care planning, treatment, service measurement and evaluation. Carers are involved in clinical redesign processes as required. Collaboration with carers provides better outcomes for the patient and minimises the risk of avoidable admission to hospital and longer lengths of stay. Carers' health and wellbeing is improved through participation in health programs that understand and are responsive to the needs of carers.	All NSW Health	MoH	Carers invited or their views considered in clinical redesign working groups and panels, including in review and evaluation mechanisms. Patient and carer feedback analysed to measure success and areas for improvement.	Each year
2.3 Fund NGOs to deliver the NSW Family and Carer Mental Health Program, and Dementia Australia NSW to deliver dementia carers support groups		MHB-MoH HSPB-MoH	NGOs	Services meet expected key performance indicators and evaluation work is conducted to ensure services are having the desired and optimal impact.	By quarter and each year
2.4 Increase carers' participation in the Get Healthy Information and Coaching Service and Stepping On falls prevention program		CPH-MoH	LHDs/SHNs	The number of carers participating in the service/program increases over each year, and concurrently improvements in carers' wellbeing are able to be identified.	Each year

Key Direction Three <i>NSW Health will support employees with caring responsibilities</i>					
Action	Benefits	Key responsibility	Partners	Indicators of success	Timeframe
3.1 Access surveys and data sources to analyse the proportion and location of employees in NSW Health with caring responsibilities, to target efforts	<p>The needs of employees who are carers are identified and initiatives are in place to respond to these.</p> <p>It is expected that a trust-based relationship and improved support will:</p> <ul style="list-style-type: none"> • Raise levels of employee satisfaction, staff retention rates and contribute to savings in the costs of staff recruitment • Enable employees to take planned leave and provide appropriate mechanisms when unplanned leave is required. 	MoH	All NSW Health	NSW Health surveys and data sources are analysed so as to support greater tailoring and targeting of approaches.	By June 2019
3.2 Develop an information pack for employees with a caring responsibility, to outline NSW Health's support for their role		LHDs/SHNs	HSPB-MoH	Information pack developed in consultation with employees with caring responsibilities. The pack to be made available across NSW Health with information to assist them balance care and work commitments.	By December 2018
3.3 Engage employees with caring responsibilities in the development of policies, guidelines and other documents that impact on them		All NSW Health	HSPB-MoH	NSW Health organisations can provide examples of how engaging employees with caring responsibilities in working groups, advisory groups and committees has led to improved outcomes for this group.	Each year
3.4 Create flexible working guidelines for management teams to effectively support to employees with caring responsibilities		WR-MoH	HSPB LHDs/SHNs Pillars Statewide Health Services Shared Services	Flexible Working Guidelines developed. NSW Health organisations are able to demonstrate examples where flexible work guidelines are implemented in a manner that reflects the principles of the NSW Carers Charter.	By June 2018
3.5 Promote policies covering leave matters and flexible work practices to employees		MoH	All NSW Health	Policies, surveys and relevant information promoted and made accessible through different channels to employees, especially those with caring responsibilities.	Each year

LEGISLATIVE and POLICY CONTEXT

NSW Carers (Recognition) Act 2010

The Act formally recognises the significant economic and social contribution of carers and commits public sector and human service agencies to key obligations and annual reporting. The Act includes a Carers Charter (see Appendix 1). As a requirement of the Act, all public sector agencies must:

- Take all reasonable steps to ensure that the members of staff and agents of the agency have an awareness and understanding of the Charter
- Have processes in place to engage and consult with carers, or organisations that represent carers, on matters that impact on carers
- Ensure human resource policies consider the needs of the public sector workforce who are carers.

In addition, as a human service agency, NSW Health employees must reflect the Charter principles in their activities. FACS provides oversight of implementation of the Act by agencies across the NSW Government.

NSW Carers Charter

The Charter contains thirteen principles that guide the way all public sector and human service agency staff should acknowledge and work with carers. It provides guidance on issues of significance for carers, including respect and recognition, inclusion in decision making, and access to services they may need.

The Charter must also be considered when developing policies, guidelines and other documents that impact on carers. This will assist in promoting the social inclusion of carers in NSW.

NSW Carers Strategy 2014-2019

The Strategy identifies five priority areas for carers including employment and education, carer health and wellbeing, information and community awareness, carer engagement and improving the evidence base for policy and practice. NSW Health is the leading agency for action areas 2.1 Easier access to health care and 4.1 Partners in care – health care.

Implementation of the Key Directions will target key actions in relation to the health and wellbeing of carers and involving carers as partners in care. A Strategy progress report is developed by FACS each year to capture activity under all priority areas.

NSW State Health Plan

The Key Directions support NSW Health policy including the NSW State Health Plan – Towards 2021. For example, Direction Three: Delivering Truly Integrated Care notes that carers are partners in the delivery of seamless, effective and efficient care.

National Safety and Quality Health Service Standards (NSQHS)

The second edition of the NSQHS Standards was endorsed by Health Ministers in June 2017, and released in November 2017. The delivery of actions under the Key Directions by NSW Health organisations may provide opportunities to build evidence to demonstrate compliance with Standards, especially Clinical Governance, Partnering with Consumers, Comprehensive Care, and Communicating for Safety. Further information about the second edition can be accessed at: www.safetyandquality.gov.au.

GOVERNANCE

The NSW Health Carers (Recognition) Act and Strategy Implementation Group is responsible for supporting delivery of the Key Directions, including monitoring and evaluation with support from the Ministry's Health and Social Policy Branch.

The Implementation Group includes representatives from LHDs, SHNs, HETI, CEC, ACI, NSW Multicultural Health Communication Service, and key Ministry branches including the Centre for Aboriginal Health, Mental Health and Workplace Relations. External partners include the FACS and Carers NSW. NSW Carer Support Services will also play an integral role in leading and influencing implementation of the Key Directions.

The Implementation Group provides:

- A cross-section of views and expertise about carers and the practical application of the Act and Strategy across NSW Health
- Advice on consultation, communication, service delivery, policy and education strategies to achieve implementation of the Key Directions.

HSPB will coordinate annual reporting against the Key Directions and provide support for statewide forums that include a focus on evaluating and planning progress under this document.

IMPLEMENTATION, MONITORING AND EVALUATION

The Key Directions will be implemented over three years across all sectors of NSW Health including the Ministry of Health, LHDs and SHNs, Pillars, Statewide Health Services, Shared Services and other health agencies. Each organisation will have responsibility for monitoring its performance against the actions under each Key Direction as appropriate.

Implementation of the Key Directions builds on significant work undertaken in previous years across the NSW public health system to continue to increase acknowledgement and support for carers.

LHDs and SHNs have a knowledgeable and highly skilled carer's support service, supported by representatives of all departments, who together will be encouraged to adopt the Key Directions and corresponding actions and tailor them to respond to local needs. Every NSW Health organisation is responsible for taking action, monitoring performance and providing evidence against actions relevant to them.

The annual NSW Health Carers Program statewide workshop is an opportunity to share examples of innovative projects, service development and evidence based approaches to improve NSW Health's responsiveness to the needs of carers.

The Implementation Group, with support from the Ministry, will develop a monitoring and evaluation plan for the Key Directions. This will measure progress in achieving the actions under each key direction and guide decisions about activities required to strengthen implementation.

An annual NSW Health report will be informed by reports on actions by each NSW Health organisation including NSW Ministry of Health branches. As required, this report will also be submitted to FACS.

APPENDIX 1: NSW Carers Charter

NSW Carers Charter

Schedule 1 of the NSW Carers (Recognition) Act 2010

A carer is someone who provides ongoing, unpaid support to people who need help because of disability, mental illness, chronic or terminal illness, dementia or frail age. Relatives and friends who provide such care, support and assistance are carers.

1. Carers make a valuable contribution to the community

- (a) NSW recognises the valuable social and economic contribution that carers make to the community.
- (b) Carers should have the same rights, choices and opportunities as other Australians.
- (c) Carers' unique knowledge and experience should be acknowledged and recognised.
- (d) The relationship between carers and the people they care for should be respected.

2. Carers' health and well-being is important

- (a) Carers should be supported to enjoy optimum health and well-being and to participate in family, social and community life, employment and education.
- (b) Carers should be supported to balance their caring role with other roles, such as work and education.

3. Carers are diverse and have individual needs within and beyond their caring role

- (a) The diverse needs of carers should be acknowledged and recognised in policy, programs and service delivery, taking into consideration culture and language, age, disability, religion, socio-economic status, place of residence, gender identity and sexual orientation.
- (b) Aboriginal and Torres Strait Islander values, heritage and concepts of caring should be respected and valued.
- (c) The additional challenges faced by carers who live in rural and remote areas should be acknowledged and recognised.
- (d) Children and young people who are carers should be supported to reach their full potential.

4. Carers are partners in care

- (a) The choices, views and needs of carers and of the people they care for should be taken into account in the assessment, planning, delivery and review of services provided to the people they care for.
- (b) Carers should be referred to, and assisted to access, appropriate supports and services.
- (c) Support for carers should be timely, responsive, appropriate and accessible.

www.facs.nsw.gov.au/carersact



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