



**Submission to the Western Australian
Department of Health**

Hospital Stay Guidelines Part 1, 2 & 3

About Carers WA

Carers WA is the peak body representing the needs and interests of carers in Western Australia and is part of a national network of Carers Associations. Carers provide unpaid care and support to family members and friends who are living with a disability, facing mental health challenges, long term health conditions (including a chronic condition or terminal illness), an alcohol or other drug dependencies, or who are frail aged. The person they care for may be a parent, partner, sibling, child, relative, friend or neighbour.

Caring is a significant form of unpaid work in the community and is integral to the maintenance of our aged, disability, health, mental health, and palliative care systems.

Some important facts about carers include:

- There are 2.65 million unpaid carers in Australia.
- There are more than 230,000 family and friends in a caring role in Western Australia or approximately 1 in 9 in the community.
- The replacement value of unpaid care, according to a report undertaken by Deloitte, Access Economics, “The economic value of unpaid care in Australia in 2020” is estimated at \$77.9 billion per annum.

Enquiries

Carissa Gautam

Systemic Policy Officer

Policy@carerswa.asn.au

Carers WA

182 Lord Street

PERTH WA 60000

Phone: 1300 227 377

Fax: (08) 9228 7488

Email: info@carerswa.asn.au

Contents

1.0 Introduction	1
2.0 Carer Identification & Recognition	1
Summary of Recommendations in Section 2:	1
3.0 Carer Inclusion & Communication	2
Summary of Recommendations in Section 3:	2
4.0 General Feedback	3
4.1 Escalation and Complaint Options	3
4.2 Case Studies.....	3
4.3 Hospital Admission Forms.....	3
Summary of Recommendations in Section 4:	4
5.0 Conclusion.....	5
APPENDIX 1: Further Feedback.....	4
Hospital Stay Guidelines, Part 1: A guide for people with disability, families and carers	4
Hospital Stay Guidelines, Part 2: A guide for disability service organisations & support workers.....	7
Hospital Stay Guidelines, Part 3: A guide for hospital staff	9

1.0 Introduction

Carers WA appreciates the opportunity to provide feedback on Parts 1, 2 and 3 of the *Hospital Stay Guideline* (the Guideline) prepared by the WA National Disability Service and the Disability Health Network on behalf of the WA Department of Health (the Department). Comments are based on ongoing feedback from carers of people with disability.

2.0 Carer Identification & Recognition

Carers WA supports and appreciates the intent of the expansion of the updated Guideline to include information and resources for people with disability, families and carers. However, we are concerned as to the lack of consistent and clear definitions, terminology and description of the rights of carers across all three sections of the Guideline.

To assist in addressing this concern, Carers WA recommends the inclusion in all three Parts of the Guideline an explanation of the *Carers Recognition Act 2004*, the Carers Charter and a definition of 'carer' as stated in the *Carers Recognition Act 2004*. While this has been included to some extent in Part 1 of the Guideline (subject to the recommended amendments in Appendix 1), it is imperative that hospital staff, disability service organisations and support workers also have easy access to this information in Parts 2 & 3 of the Guideline to ensure consistent identification and inclusion of carers across the hospital stay process.

To ensure further clarity in regard to the terminology used in the Guidelines, Carers WA recommends the inclusion of a glossary of definitions in each part of the guide. In addition, consistency throughout the draft documents of a clearly defined term for unpaid 'carer' would further assist in achieving clarity, in place of mixed and interchangeable terminology to explain the support network. i.e. 'support worker', 'guardian', 'carer', 'stakeholder', 'key supports', 'representative' and 'support person'.

Summary of Recommendations in Section 2:

- An explanation of the *Carers Recognition Act 2004*, the Carers Charter and a definition of 'carer' as stated in the *Carers Recognition Act 2004* be included in all Parts;
- A glossary of definitions be included in all Parts;
- One clearly defined term for unpaid 'carer' be used consistently across all Parts;

3.0 Carer Inclusion & Communication

Carers WA is supportive of the intent and aims of the Guidelines in outlining the best practice approach for the management of the hospital experience of individuals with disability. However, this intent is unlikely to be achieved in practice without proper commitment to the roles and responsibilities described by all stakeholders.

Without proper engagement, inclusion and communication with the carer by the hospital staff and other stakeholders, the carer is not able to effectively perform their roles and responsibilities or best care for the individual. Should the carer not be recognized, involved and informed as per the requirements of the *Carers Recognition Act 2004*, they are not able to plan for stated responsibilities such as having transport and services ready upon discharge. This is a particular concern should discharge occur at times such as the 2am stated in Part 1 of the Guideline, with potential risk to the individual involved if their carer (if applicable) is not able to be present for discharge.

To address this issue and ensure adherence to the responsibilities covered in the Guidelines and in the *Carers Recognition Act 2004*, Carers WA recommends that hospital staff, disability service organisations and support workers be required to undertake protected training on the requirements for the identification, recognition, inclusion and communication with carers, as outlined under the *Carers Recognition Act 2004*.

To further support the need for this recommended measure, the recently released *Review of the Carers Recognition Act 2004: Report to Parliament* included recommendations to:

- *'Recommendation 1: Develop and implement a multi-faceted campaign, including training, to raise service provider and community awareness of carers, the Act, the Carers Charter and the WA Carers Strategy'*.
- *'Recommendation 5: Develop resources to support consistent understanding and application of the Carers Charter by organisations and service providers'*.

Summary of Recommendations in Section 3:

- Hospital staff, disability service organisations and support workers be required to undertake protected training on the requirements for the identification, recognition, inclusion and communication with carers, as outlined under the *Carers Recognition Act 2004*.

4.0 General Feedback

4.1 Escalation and Complaint Options

One of the findings of the *Review of the Carers Recognition Act 2004: Report to Parliament* was that *'further action is required to achieve wider carer and service provider awareness of a carer's right to lodge complaints, and where and how to lodge them'*.

The recommendation to address this finding was:

- *'Recommendation 6: Develop and implement initiatives to raise awareness amongst:*
 - *Carers of their right to lodge a complaint about non-compliance, and how and where to lodge one*
 - *Service providers of carers' right to lodge complaints and providers' responsibilities to facilitate complaint lodging and resolution'*.

Further to the above finding and recommendation, Carers WA recommends all Parts of the Guidelines include information informing and educating both carers and service providers on the carer's right to lodge complaints and escalation options where appropriate. i.e. Such as the Health & Disability Complaints Office, Carers WA Advisory Service and Health Consumers Council.

4.2 Case Studies

The inclusion of case studies in Part 3 of the Guideline is considered to be a good tool towards demonstrating to hospital staff the practical application of the roles and responsibilities discussed in the Guidelines.

However, Carers WA would recommend the addition of a brief or paragraph at the end of each case study, to further discuss and clarify the application of the roles and responsibilities demonstrated in each case study.

4.3 Hospital Admission Forms

Carers WA recommends inclusion of a requirement in the Guidelines for hospitals to update hospital admission forms to reflect the requirements of the Guidelines, inclusive of a checkbox for 'Does this person have a carer and/or guardian?', space for carer and/or guardian details and a definition of the term 'carer' as defined under the *Carers Recognition Act 2004*.

Summary of Recommendations in Section 4:

- Information for carers and service providers on the carer's right to lodge complaints, escalation options and how to proceed with them be included in all Parts of the Guidelines;
- A brief or paragraph be included after each case study in Part 3, clarifying and discussing the application of roles and responsibilities in each case;
- Requirement to be included to update hospital admission forms to reflect requirements of the Guidelines, inclusive of carer identification, record of carer and/or guardian details and a definition of the term 'carer' as defined under the *Carers Recognition Act 2004*.

5.0 Conclusion

Should any further information be required regarding the comments included within this submission, or assistance from the perspective of carers, Carers WA would be delighted to assist. Please contact Carissa Gautam from Carers WA at policy@carerswa.asn.au.

APPENDIX 1: Further Feedback

Hospital Stay Guidelines, Part 1: A guide for people with disability, families and carers		
Section and Page	Quote	Carers WA Feedback
Introduction, page 1	'This guide has been developed to assist people with disability and their support networks to be better prepared and have more confidence when interacting with hospital staff when.'	Recommended inclusion and definitions of what is included in the term 'support networks' – i.e. Families, carers, etc.
Keep connected with the GP, page 1	'Attending an emergency department at a hospital should be a last resort.'	Recommended amendment to 'Your GP should be the first option for medical assistance for non-urgent and general medical concerns, with the emergency department to be attended in the case of an emergency or urgent medical concerns. – concern the use of 'last resort' terminology may result in hesitation to attend ED in the case of an emergency.
Taking someone in your care to hospital, page 2.	'Or have access to a device to assist with communication.'	Recommended inclusion of examples of communication devices.
Taking someone in your care to hospital, page 2.	'To support a person with a Development Disability or an intellectual impairment to prepare for a hospital visit, the following creative strategies may assist.'	Recommended inclusion of information on where the devices listed under 'creative strategies' may be obtained either for free or at a subsidized rate for carers/family of or for people with a disability.
Being prepared for a planned admission, page 3	'4. Take the Individual Health Profile and Health Passport.'	Recommended amendment to '4. Take the Individual Health Profile, Health Passport and any other applicable documentation. i.e. Guardianship, Care Plan and Advanced Health Directive documentation.'
What to Pack, page 4	Documentation	Recommended inclusion of documents in checklist 'Guardianship, Advanced Health Directive, Care Plan and any other applicable documentation'
Individual Health Profile Form		Recommended inclusion on Individual Health Profile Form of:

APPENDIX 1: Further Feedback

		<ul style="list-style-type: none"> - Checkbox for a question ‘Does this person have a carer and/or guardian?’ - Inclusion of space for carer and/or guardian details
During Hospital, page 6		Concern that despite the guidance given on roles throughout varying parts of the hospital stay, that this will not assist carers without appropriate communication and recognition by hospital staff.
During Hospital, page 6		Recommended addition of dot point: <ul style="list-style-type: none"> • ‘Advise hospital staff of carer and/or guardian details and provide copies of relevant documentation. i.e. Guardianship and Advanced Health Directive documentation if applicable.
Triage, page 7	‘keep the individual comfortable and ensure they do not become distressed’	Recommended inclusion of guidance on actions to take if distress occurs. i.e. who to contact.
Care Call, page 8	‘In the adult system you can speak to the Nurse Coordinator on the ward or contact the ‘Patient and Family Liaison Officer’ to express your concerns.’	Recommended inclusion of the next step of escalation should carer or family concerns not be acknowledged. i.e. Health & Disability Complaints Office; Carers WA Advisory Service; Health Consumers Council.
The Roles and Rights of Carers in Hospital, page 8	‘Part of your role as a support person...’	Recommended inclusion of definition of what is included in term ‘support person’
The Roles and Rights of Carers in Hospital, page 8		Recommended inclusion of a definition of a carer as per the WA Carers Recognition Act 2004. <p>‘Under the WA Carers Recognition Act 2004, a person is a carer if they provide ongoing care or assistance to:</p> <ul style="list-style-type: none"> • a person with disability; • a person who has a chronic illness, including a mental illness; • a person who, because of frailty, requires assistance with carrying out everyday tasks; or

APPENDIX 1: Further Feedback

		<ul style="list-style-type: none"> • a person of a prescribed class.’
The Roles and Rights of Carers in Hospital, page 8	‘The Western Australian Carers Recognition Act 2004 and the Carers Charter outline how carers are to be treated and involved in delivering <u>some</u> services which impact on them. Hospitals and health workers must comply with this.’	<p>Recommended removal of underscored word ‘some’.</p> <p>Recommended inclusion of information or where to get information on what to do when hospitals and health workers do not comply with the WA Carers Recognition Act 2004 and the Carers Charter. i.e. Health & Disability Complaints Office; Carers WA Advisory Service; Health Consumers Council.</p>
The Roles and Rights of Carers in Hospital, page 8	<p>The Western Australian Carers Charter states that:</p> <ul style="list-style-type: none"> • Carers must be treated with respect and dignity • The role of carers must be recognised by including carers in the assessment, planning, delivery, and review of services that impact on them and their role as carer • The views and needs of carers must be considered along with the views, needs and best interests of people receiving care when decisions are made that impact on them and their caring role • Complaints made by carers in relation to services that impact on them, and their role must be given due attention and consideration. 	<p>Recommended corrections to the following errors in the Carers Charter:</p> <ul style="list-style-type: none"> • The role of carers must be recognised by including carers in the assessment, planning, delivery, and review of services that impact on them and their role as carer, • The views and needs of carers must be considered taken into account along with the views, needs and best interests of people receiving care when decisions are made that impact on them and their caring role carers & the role of carers.
Who is responsible for what?, page 10	<ul style="list-style-type: none"> • Planning and preparation for a patient to discharge 	<p>Inclusion on end of dot point of: ‘...inclusive of engagement with patient’s support network (carers, family, etc)</p>

APPENDIX 1: Further Feedback

Preparing to go home, page 11	‘when the individual is discharged from ED...’	Concern that despite the guidance given on roles throughout varying parts of the hospital stay, that this will not assist carers without appropriate communication and recognition by hospital staff.
Preparing for Discharge from hospital admission, page 11		Recommended inclusion of a dot point: <ul style="list-style-type: none"> ‘Arrangements for applicable support services to recommence on hospital discharge’

Hospital Stay Guidelines, Part 2: A guide for disability service organisations & support workers		
Section and Page	Quote	Carers WA Feedback
Part 2 of Guideline		Recommended inclusion of ‘paid’ before reference to ‘support worker’ in Part 2 of the Guideline, where appropriate. This will assist in differentiating the difference between a paid support worker and an unpaid family and/or friend carer.
Introduction, page 1	‘A person with disability may have:’	Recommended inclusion of dot point: <ul style="list-style-type: none"> ‘Need for the assistance of a family and/or friend carer, including but not limited to involvement in patient care and planning.’
The Role of Support Workers in Hospital, page 2		Recommended inclusion of definition of ‘support worker’ and how this role differs from that of an unpaid family and/or friend carer.
The Role of Support Workers in Hospital, page 2	‘In the hospital, you can speak to the Nurse Coordinator on the ward. If you wish to make a complaint, liaise with the ‘Patient and Family Liaison Officer’.’	Recommended inclusion of the next step of escalation should support worker concerns not be acknowledged. i.e. Health & Disability Complaints Office; Carers WA Advisory Service; Health Consumers Council.

APPENDIX 1: Further Feedback

The Role of Support Workers in Hospital, page 2	'The following are some common concerns reported during a hospital experience:'	Recommended inclusion of dot points: <ul style="list-style-type: none"> 'Lack of communication with family and/or friend carer.'
The Role of Support Workers in Hospital, page 2	<ul style="list-style-type: none"> 'Lack of parent/carer training' 	Recommended amendment to: <ul style="list-style-type: none"> 'Lack of family and/or carer training & involvement in patient care.'
In the Emergency Department, page 3		Recommended inclusion of dot point: <ul style="list-style-type: none"> 'Advise the hospital staff of carer name and contact details.'
In the Emergency Department, page 3	<ul style="list-style-type: none"> Keep the individual comfortable and ensure they do not become distressed 	Recommended inclusion of information on actions to take and who to contact should individual become distressed.
In the Emergency Department, page 3	<ul style="list-style-type: none"> Be prepared to advocate for the individual if required (speak up if you think the individual is deteriorating and you have concerns). 	Recommended inclusion of who to speak to and escalation options should concerns not be acknowledged.
In the Emergency Department, page 3	'The DSO staff or carer should be aware that they may be included in a case conference around the health care management plan for the individual.'	Recommended amendment to 'they should be'.
Planning and preparation for admission to hospital, page 4	'Inform and involve the individual's representative in planning for the admission, where appropriate'	Recommended clarification of the term 'representative' and inclusion of further information on where informing and involving would be 'appropriate'.
During Admission, page 5		Recommended inclusion of dot point: <ul style="list-style-type: none"> Inclusion of family, carer and/or guardian in patient care and planning
During Admission, page 5		Recommended inclusion of details in the 'During Admission' section in Part 1 of the Guidelines as well.

APPENDIX 1: Further Feedback

Appendix 3 – Packing Checklist, page 11	‘Checklist of what to take to hospital for the person you support:’	Recommended inclusion of dot point: <ul style="list-style-type: none"> • Details of family, carer and/or guardian and any applicable documentation. i.e. Advanced Health Directive, Care Plan and Guardianship documentation.
Appendix 5 – Individual Health Profile, page 14		Recommended inclusion on Individual Health Profile Form of: <ul style="list-style-type: none"> - Checkbox for a question ‘Does this person have a carer and/or guardian?’ - Inclusion of space for carer and/or guardian details

Hospital Stay Guidelines, Part 3: A guide for hospital staff		
Section and Page	Quote	Carers WA Feedback
Part 3		Recommended inclusion of sections in Part 3 on ‘The Roles and Rights of Carers in Hospitals’ and ‘Arranging Support Network Attendance’ – Suggested inclusion after Section ‘Arranging service provider attendance’ on page 7.
Supporting the Individual during their Hospital Admission – Process Flowchart	1. Gather background information: <ul style="list-style-type: none"> - Identify the support network 	Recommended inclusion of clarification on what ‘support network’ includes. i.e. carer and/or family, guardian, etc.
Supporting the Individual during their Hospital Admission – Process Flowchart	2. Set expectations early	Recommended inclusion of ‘Arranging attendance of support network at early stakeholder case conference (i.e. carer and/or family, guardian, etc.)
Supporting the Individual during their Hospital Admission – Process Flowchart	5. Discharge planning	Recommended amendment of ‘Discharge plan coordination’ to ‘discharge plan coordination with inclusion of support network. i.e. carer and/or family, guardian, etc.
Key Summary, page 1		Recommended clarification of differentiation between ‘support network’ and ‘support person’, and clarity on inclusions within the ‘support network’. Recommended inclusion in recommended glossary.

APPENDIX 1: Further Feedback

		<p>Recommended inclusion of dot point:</p> <ul style="list-style-type: none"> Identify the person's support network involved in their care and document their contact details.
Establishing Functional Support Needs, page 2	'If the patient is unable to do so themselves, ask their support workers to provide...'	Recommended inclusion of 'support workers and carer'.
Booking an early stakeholder case conference, page 6	'...early case conference with all stakeholders to discuss...'	Recommended definition of term 'stakeholders', with an emphasis that this group is inclusive of the carer (if applicable), which may be a family member or a friend.
Delivering excellent communication, page 10	'The following resources and guidelines are available to assist staff to implement excellent communication standards and processes...'	Recommended inclusion of a dot point linking to the <i>Carers Recognition Act 2004</i> and subsequent summary, as per the other items on the list.
Appendix 1: Individual health profile template example, page 21		<p>Recommended inclusion on Individual Health Profile Form of:</p> <ul style="list-style-type: none"> - Checkbox for a question 'Does this person have a carer and/or guardian?' - Inclusion of space for carer and/or guardian details
Appendix 5: Caring for people with Disability	<p>Support Networks</p> <ul style="list-style-type: none"> Identify whether my family and carers are a critical part of my support 	<p>Recommended amendment of dot point to:</p> <ul style="list-style-type: none"> Identify whether my family and carers are a critical part of my support and document need for inclusion in patient care and planning, subject to requirements of the <i>Carers Recognition Act 2004</i>.
Appendix 7		Recommended inclusion of an additional Appendix in Part 3, identical to Appendix 1, Other Resources from Part 1.