Information Package for:

Neurological Needs Checklist for patients with long term neurological conditions
## Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What is this Package?</td>
<td>2</td>
</tr>
<tr>
<td>2. About the Checklist</td>
<td>2</td>
</tr>
<tr>
<td>2.1 What is the aim of the Checklist?</td>
<td>2</td>
</tr>
<tr>
<td>2.2 How was the Checklist developed?</td>
<td>3</td>
</tr>
<tr>
<td>2.3 Why do we need this Checklist?</td>
<td>3</td>
</tr>
<tr>
<td>2.4 How to use this Checklist: Health Professionals</td>
<td>4</td>
</tr>
<tr>
<td>2.5 How to use this Checklist: Patient/carers or family</td>
<td>5</td>
</tr>
<tr>
<td>3. About the Resources to be used with the Checklist</td>
<td>6</td>
</tr>
<tr>
<td>3.1 Neurological Needs Checklist – Services Information</td>
<td>6</td>
</tr>
<tr>
<td>3.2 Neurological Needs Checklist - Glossary</td>
<td>6</td>
</tr>
<tr>
<td>4. The Neurological Needs Checklist</td>
<td>6</td>
</tr>
<tr>
<td>5. The Neurological Needs Checklist - EASY READ VERSION</td>
<td>7</td>
</tr>
<tr>
<td>6. Neurological Needs Checklist - Services Information</td>
<td>7</td>
</tr>
<tr>
<td>7. Neurological Needs Checklist - Glossary</td>
<td>8</td>
</tr>
<tr>
<td>8. References</td>
<td>8</td>
</tr>
</tbody>
</table>

Prepared by Training Centre in Subacute Care (TRACS WA), WA Health in conjunction with the Subacute Care Community of Practice, December 2013
1. What is this Package?

This information package provides a simple guide to help patients, carers, family and clinicians to understand what the **Neurological Needs Checklist** is and how to use it.

The package includes:

- Background and instructions for using the Checklist
- The Neurological Needs Checklist
- The Neurological Needs Checklist – Easy Read Version
- The Neurological Needs Checklist - Services Information
- The Neurological Needs Checklist- Glossary

The resources included in this kit were developed with subacute care clinical staff, expert clinicians and academics in W.A., General Practitioners and Consumers.

2. About the Checklist

2.1 What is the aim of the Checklist?

The Neurological Needs Checklist aims to **help people with neurological conditions** (and the people supporting them) to:

1. talk to their GP or healthcare professional, acting as a prompt for common problems.
2. be aware of common problems with chronic neurological conditions and the actions that could be taken, if any of these common problems do arise.
3. take an active role in seeking timely advice or assistance in order to maintain health and wellbeing.

The Neurological Needs Checklist aims to **help clinicians** to:

1. help identify any common problems or complications of chronic neurological conditions experienced by their patient, that may be amenable to treatment and/or referral
2. be aware of common problems with chronic neurological conditions and the actions that could be taken, if any of these common problems do arise
3. support the patient to monitor for any commonly occurring and troubling complications at their annual review.
2.2 How was this checklist developed?

This **Neurological Needs Checklist** for patients with chronic Neurological conditions is adapted from the Post Stroke Checklist (PSC) (Philp et al 2012)\(^1\) developed with the support of measurement experts, international stroke experts, and post-stroke care stakeholders. A list of long-term post-stroke problem areas was generated by an international, multidisciplinary group of stroke experts. Using well accepted research methodology, a consensus was reached on which problem areas on the list were most important and relevant to include in a PSC and how best to ask about post-stroke problem areas.

The PSC is recommended by the National Stroke Foundation (NSF)\(^2\). It has been adapted in consultation with WA health professionals and consumers, so that it can be a useful tool for people with other neurological conditions (such as Parkinson’s Disease, Motor Neuron Disease, Multiple Sclerosis, and Acquired Brain Injury). It is can also be useful for those people who haven’t got a specific diagnosis for their neurological condition.

It is accepted that people who have a stroke make up a large proportion of those with chronic neurological conditions (World Health Organisation, 2006)\(^3\). However those with chronic neurological conditions other than stroke do not appear to be equally well represented in the literature and the long-term risks they face have not been as succinctly articulated as in the PSC. The **Neurological Needs Checklist** for patients with chronic neurological conditions has been adapted with the aim of filling this gap. As such it will be require further development and validation.

2.3 Why do we need this Checklist?

Long-term care for people with neurological conditions (for example stroke) is fragmented and lacks an evidence based, easy-to-use tool to identify persistent long-term problems (Philp et al 2012)\(^1\).

There are many people in W.A. living with a chronic neurological condition. It is people with these conditions that may benefit from a tool that helps them to monitor and manage the common problem areas they experience.

While available incidence and prevalence data is inconsistent, data from reliable sources indicates that there are many people in W.A. living with neurological conditions. For example there are approximately:

- 20,000 with Epilepsy on average in WA\(^4\)
- 2135 with Multiple Sclerosis on average in WA\(^5\)
- 132 people with Motor Neuron Disease on average in WA\(^6\)
- 22,710 hospital admissions for Traumatic Brain Injury nationwide (2004-05)\(^7\)
- 100 000 people estimated living with Parkinson’s Disease nationwide\(^8\)

There are a number of factors that put people with chronic neurological conditions at greater risk of experiencing complications related to their condition.

- High level of loss to follow up for some clinical groups such as traumatic brain injury (Corrigan, 2003)\(^9\)
- Difficulty accessing ongoing relevant community therapy services (Rimmer and Henley, 2013)\(^10\)
• Less frequent/ lower priority specialist medical follow-up (as compared to more acute conditions)

It can be clinically difficult to identify some of the risks for people with chronic neurological conditions in order to prevent complications or early deterioration. Health Professionals with limited exposure may find it more difficult. A recent survey of 200 subacute care staff in W.A. indicated that while the majority of staff had been practicing for more than 10 years, 30% of respondents had 0-3 years experience in subacute care. These staff may have limited experience identifying risks/ potential problems in these chronic neurological populations (Source: 2013 TRACS WA Inaugural Consumer Satisfaction Survey)

This Checklist will support patients and clinicians to identify any common problems and complications of chronic neurological conditions that may be experienced. It will assist to direct patients to appropriate treatment options and/or referral to specialist services.

2.4 How Health Professionals can use the Checklist:

Patients’ needs change over time, so it important to use this checklist at each point of contact with health services. The Checklist can be completed with the patient during a scheduled review (e.g. by GP, Allied Health Professional or Community Nurse).

It would be useful to have a copy of the Checklist available prior to your contact with the patient. Ask the patient each numbered question and indicate the answer in the “Response” section.

<table>
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<tr>
<th>QUESTION</th>
<th>RESPONSE</th>
<th>ACTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Daily Living</td>
<td>NO</td>
<td>YES</td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Are you finding it more difficult to take care of yourself? e.g. Do you have difficulty/issues with: dressing, washing and/or bathing? preparing hot drinks and/or meals? getting outside, doing household chores or driving? special equipment (e.g. shower chair, wheelchair)?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Moving Around</td>
<td>NO</td>
<td>YES</td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Are you finding it more difficult to walk and/or more difficult to move safely from bed to chair lately? Have you had any falls or nearly fallen in the last 12 months?</td>
<td></td>
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Generally if the answer is NO, update the patient record and plan to review the question at a future contact point, as appropriate. If the response is YES, follow-up with the appropriate action/s. The simple scoring rubric enables health professionals to track change in individuals and groups over time.

To assist clinicians to make an appropriate onward referral, a list of options for referral and relevant contact details for WA services, mentioned in the Checklist is available in Section 3.1 (Services Information). The Services Information can be given to the patient, carer and or family member in situations where self-referral is an appropriate option.
Health Professionals should provide patients, carers and/or a family member with a copy of the Checklist and Glossary:

- On discharge from regular allied health therapy services
- When the patient is receiving maintenance programs or periodic reviews,

The **EASY READ VERSION** should be offered to patients or families for whom this may be more appropriate.

Clinicians should encourage their patients to use this Checklist *every 6-12 months*. If problems are identified between annual/scheduled reviews, which are not being managed by another specialist or treating team, then this tool could be useful to help a patient to identify the need to arrange an earlier GP review.

It is important to discuss with patients what services are realistically available. Patients, carers or family members should to be advised that if a problem or need is identified, services may or may not be available in their area – or there may be long waiting periods to access services.

If patients are keen to seek services through private therapists – the patient should be given guidance to ensure they can locate a clinician that has an interest/ speciality in treating neurological conditions specifically.

### 2.5 How Patients, their Carers or Family can use the Checklist:

The Checklist has been designed to help you talk to your GP or healthcare professional, by prompting consideration of common problems.

The Checklist has many sections because the changes caused by a neurological condition may affect many areas of life. Time should be taken to consider each area. It is important to remember that every person is different and some people with a chronic neurological condition might not experience problems in any area and others will experience problems in many different areas. Not everyone will experience problems.

The Checklist can be filled in by you, your carer or family member. Read each question and mark on the checklist whether you are having any problem in this area of your life by ticking either Yes or No in the relevant box.

**You should take the checklist with you when you visit** your GP or health care professional to help raise relevant problems and discuss any actions that might be appropriate.

An **EASY READ VERSION** of the Checklist is available. If you would prefer to use this version, you should ask your G.P or health professional to provide a copy. It contains the same information presented in a different layout, with larger print and supporting visual/ graphic information. You should read each section (13 areas, with questions in each) and note whether you are having any problem in this area of your life. There is space available for notes, to write down any details relating to each area.

For ease of reference the problem areas can be summarised in the box on the back page of the **EASY READ VERSION**. Also the date the Checklist is completed should be noted to keep track of how you are going over time.
Other supporting information that you may find helpful when completing the checklist:

- The Neurological Needs Checklist - Services Information, which gives details about services that may assist (see section 3.1)
- The Neurological Needs Checklist – Glossary, which explains some of the terms in the Checklist (see section 3.2)

Problems often change over time, so it is recommended to use this Checklist at least every 6-12 months or at annual reviews with the G.P or other health professionals.

3. About the Resources to be used with the Checklist

3.1 Neurological Needs Checklist - Services Information

The Services Information is a compilation of relevant WA service providers, including primary contact details. Services included in the list are those that are noted as possible options in the actions for each problem area considered in the Checklist.

This document is designed to assist clinicians to make onward referrals to appropriate services. Alternatively the relevant service details can be given to the patient, carer or a family member in situations where self referral is an appropriate and feasible option.

3.2 Neurological Needs Checklist- Glossary

The Glossary contains explanatory information, in consumer friendly format, to assist the patient, carer and or family member to understand the terminology used in the Checklist.

The Glossary should be given to the patient, carer or family member to support understanding and appropriate use of the tool. Neurological Needs Checklist

This double sided checklist is also available directly from TRACS WA upon request. It is designed for printing in colour.
5 The Neurological Needs Checklist – EASY READ VERSION

This is an 8 page version of the tool with simple wording and illustrations for those who may need it.

A Printable PDF version is also available directly from TRACS WA upon request.

6 The Neurological Needs Checklist – Services Information

This is a 5 page document listing relevant WA health service providers mentioned in the Checklist.

A printable PDF version is also available directly from TRACS WA upon request.
7 The Neurological Needs Checklist – Glossary

This is a 4 page document with consumer friendly, layman explanations of health and medical terminology used in the Checklist.

A Printable PDF version is also directly from TRACS WA upon request.

8. References


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