

# CORE STANDARDS FOR NURSES WHO SUPPORT PEOPLE WITH A DISABILITY

## WORKING WITH PEOPLE WITH CHRONIC AND COMPLEX HEALTH CARE NEEDS APPRAISAL

This appraisal is a guide to support nurses in discussing how to support people with a disability who have chronic and complex health care needs. It covers what nurses need to be mindful of when supporting people who have chronic and complex health conditions and highlights the particular problems associated with their disability. Prior to this appraisal being completed nurses should have read and understood the other practice packages titled Person Centered Health Care Assessments and the development of Health Care Plans and Communication & Behaviour Support, and Mealtime Management. It is important for each nurse wanting to be assessed to arrange a time with the Work Practice Support Person (WPSP) and use this as part of your professional supervision sessions.

It is important when supporting people with a disability to note that there may be challenges in developing and maintaining health care /services for someone who has chronic and complex health care needs and nurses need to work as part of a transdisciplinary approach.

**NURSE:****Date Core Standard commenced:****POSITION:****WORK PRACTICE SUPPORT PERSON NAME:****Date Core Standard commenced:****POSITION:****DEFINITIONS:**

**Work Practice Support Person (WPSP):** this person supports the nurse and can be a professional supervisor or management supervisor with appropriate skills and experience. An alternative WPSP may be identified if the current supervisor/s believe another person may be better suited to assessing a nurse's knowledge. Consideration must be given to the professional discipline of the supervisee to ensure an appropriate WPSP is selected.

**GUIDELINES:**

- The WPSP will sign below when they are satisfied the requirements for each section below have been met. The information under each question is intended to provide the key points each nurse should address. Nurses can provide more than is itemised.
- Questions may be answered verbally or in writing.
- Questions may be answered in the context of a group discussion as long as the WPSP is present and satisfied with the nurse's response.
- Case discussion / examples are acceptable if completed in collaboration with another nurse as long as the WPSP can identify the nurse's level of contribution and is satisfied that the requirements are met.
- Case discussion / examples must have been completed within the previous 12 months.
- There is not a scoring system in this appraisal. All questions to be answered to a satisfactory level.

## **DISCLAIMER:**

This appraisal was developed by the Clinical Innovation and Governance Directorate of Ageing, Disability and Home Care in the Department of Family and Community Services, New South Wales, Australia (FACS).

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## **CERTIFICATION:**

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Skills that are appraised only once can wane over time through lack of use, monitoring and feedback. It is suggested that certificates of completion be renewed every four years. To ensure this is easy to do participants need only re-submit two further case examples demonstrating application of the information covered by the core standard program.

Questions / Answers	Comments	Meets Requirements (WPSP)
<b>INTRODUCTION TO THE CHRONIC AND COMPLEX HEALTH CARE NEEDS</b>		
<b><i>DYSPHAGIA</i></b>		
<p><b>List some of the issues that Nurses need to consider when supporting a person who has dysphagia?</b></p> <ul style="list-style-type: none"> <li>▪ completion of the Nutrition and Swallowing Checklist</li> <li>▪ referral to specialists</li> <li>▪ modified barium swallow/Barium via PEG</li> <li>▪ infant feeding</li> <li>▪ menus, recipes, portions</li> <li>▪ safe storage and handling of food</li> <li>▪ textures of food and drink and how to achieve them</li> <li>▪ supplements and how to add them</li> <li>▪ alternatives to oral eating and drinking – benefits, risks, ethics, family issues</li> <li>▪ nasogastric tube feeding</li> <li>▪ pre- and post-operative care of gastrostomy tube</li> <li>▪ enteral feeding regimes – rate and timing</li> <li>▪ maintenance and replacement of enteral feeding tubes</li> <li>▪ maintenance and safe handling of enteral feeding equipment</li> <li>▪ plan for dislodged tube</li> <li>▪ stoma care</li> <li>▪ oral care</li> <li>▪ positioning</li> <li>▪ specialised eating and drinking equipment</li> <li>▪ financial assistance for specialised equipment, formula and supplements through FACS's AIDAS program or Enable's Home Enteral Nutrition (HEN) program</li> <li>▪ self-feeding programs</li> <li>▪ environments for eating and drinking</li> <li>▪ coughing and gagging</li> <li>▪ aspiration</li> <li>▪ sleep patterns</li> <li>▪ weight</li> </ul> <p>Further details can be found in: <i>Mealtime Management Practice Package</i>. (Burton, Cox &amp; Sandham, 2009; Crawford, 2009; Kenny &amp; Goodman, 2010; Sleigh, 2005; Therapeutic Guidelines, 2012)</p>		

Questions / Answers	Comments	Meets Requirements (WPSP)
<b>GORD AND <i>HELICOBACTER PYLORI</i></b>		
<p><b>What are the signs of GORD and <i>Helicobacter pylori</i> infection a Nurse must be alert to, especially in people who cannot relate their symptoms?</b> These signs may include:</p> <ul style="list-style-type: none"> <li>▪ burping</li> <li>▪ regurgitation</li> <li>▪ vomiting</li> <li>▪ hand-mouthing</li> <li>▪ dental erosion</li> <li>▪ loss of appetite</li> <li>▪ weight loss</li> <li>▪ depleted iron stores</li> <li>▪ challenging behaviour</li> </ul>		
<p><b><i>Gastroenteritis</i></b>  <b>What are the primary concerns with acute gastroenteritis are aspiration and dehydration</b>  <b>The nurse considers:</b></p> <ul style="list-style-type: none"> <li>▪ standard precautions</li> <li>▪ severity of acute episode, likelihood of dehydration – can be managed at home with/without assistance of GP or requires hospitalisation for IV treatments and/or co-morbidities, e.g. epilepsy medication</li> <li>▪ management of vomiting through medication, e.g., IM Maxolon</li> <li>▪ management of aspiration through positioning and oral care</li> <li>▪ management of dehydration through fluid and electrolyte replacement, e.g., Gastrolyte</li> <li>▪ management of pain/fever with cooling methods and/or medication, e.g., Panadol</li> <li>▪ stool sample for culture</li> <li>▪ management of diarrhoea with medication, e.g., Immodium (with care)</li> <li>▪ perineal care</li> <li>▪ slow resumption of low-irritant diet</li> <li>▪ slow resumption of formula for a person who receives nutrition and fluids via enteral feeding</li> </ul>		
<b>RESPIRATORY HEALTH</b>		
<p><b>What are the issues a Nurse needs to consider when support a person who has respiratory health issues?</b></p> <ul style="list-style-type: none"> <li>▪ chest management plan</li> <li>▪ annual Fluvax</li> <li>▪ Pneumovax (some discussion re adverse effects of second dose)</li> <li>▪ how to integrate the Physiotherapy plan into the person's daily activities</li> <li>▪ sleep patterns</li> <li>▪ exercise tolerance</li> <li>▪ smoking</li> </ul>		

Questions / Answers	Comments	Meets Requirements (WPSP)
<ul style="list-style-type: none"> <li>▪ equipment required, eg, wedges, electric bed</li> <li>▪ oral suction (tracheal suction not recommended)</li> <li>▪ percussion and drainage</li> <li>▪ oral care</li> <li>▪ management of drooling, eg, Botox</li> <li>▪ inhalants – puffer, spacer, nebuliser followed by oral care</li> <li>▪ respiratory rate</li> <li>▪ pulse oximetry</li> <li>▪ oxygen (rate prescribed by doctor)</li> <li>▪ maintenance, hygiene and replacement of equipment</li> <li>▪ financial assistance for equipment</li> <li>▪ triggers for asthma</li> <li>▪ safety of heating, e.g. noxious fumes from unflued gas heating</li> <li>▪ moisture of air</li> <li>▪ household hygiene, e.g., dust, pillows</li> <li>▪ pets</li> <li>▪ household maintenance, e.g., painting, building</li> <li>▪ prophylactic and/or early introduction of antibiotics</li> <li>▪ management of acute episodes at home or in hospital</li> </ul> <p>For people with recurrent chest infections and/or chronic lung disease, regular reviews with a GP or respiratory physician are recommended. They can help develop a chest management plan. Good chest management prevents threats to health and is best done in collaboration with a Physiotherapist who can devise an individualised regime of positioning, movement and exercise for a person with respiratory health problems.</p>		
<p><b><i>Management of Acute Asthma</i></b></p> <p><b>List several issues a Nurse needs to consider when supporting a person who has asthma?</b></p> <ul style="list-style-type: none"> <li>▪ coughing</li> <li>▪ wheezing</li> <li>▪ breathlessness</li> <li>▪ distress</li> <li>▪ response to medication</li> <li>▪ fever</li> <li>▪ previous history</li> <li>▪ human resources</li> <li>▪ follow up, eg, review medications and action plan with GP</li> </ul>		

Questions / Answers	Comments	Meets Requirements (WPSP)
<p><b>What will be the nurse’s plan of action in support the person?</b></p> <ul style="list-style-type: none"> <li>• Management of acute asthma depends on the severity of the exacerbation</li> <li>• Ensure the person has an updated asthma management plan developed and endorsed by GP.</li> <li>• Person understands their asthma management plan</li> <li>• Medications have been reviewed and medications are in date</li> <li>• Asthma management plan should identify triggers for the person to avoid.</li> <li>• For mild and moderate attacks, the asthma action plan should indicate the steps to take, e.g., use of Ventolin, oxygen, prednisolone. For severe attacks, transfer the person to hospital.</li> </ul>		
<p><b>Management of Chest Infection/Aspiration Pneumonia</b></p> <p><b>What are the issues Nurses need to consider when supporting a person?:</b></p> <ul style="list-style-type: none"> <li>▪ respiratory rate</li> <li>▪ oxygen saturation</li> <li>▪ chest sounds</li> <li>▪ coughing</li> <li>▪ fever</li> <li>▪ response to fever-reducing medication/treatments</li> <li>▪ response to suction</li> <li>▪ sputum culture</li> <li>▪ response to antibiotics (oral or enteral tube)</li> <li>▪ co-morbidities, e.g., seizures increasing, vomiting with coughing</li> <li>▪ previous history</li> <li>▪ GP and/or specialist recommendations</li> <li>▪ family wishes</li> <li>▪ human resources</li> <li>▪ follow up, e.g., review chest management with respiratory physician</li> </ul> <p>This too will depend on the severity of the chest infection. The person may be managed at home with assistance from the GP or transferred to hospital for IV antibiotics.</p>		
<p><b>Management of Tracheostomy, Mechanical ventilation, CPAP (Continuous Positive Airway Pressure), BiPAP (Bi-level Positive Airway Pressure)</b></p> <p>Some people are assisted to breathe using invasive</p>		

Questions / Answers	Comments	Meets Requirements (WPSP)
<p>(tracheostomy) or non-invasive (CPAP, BiPAP) methods.</p> <p><b>What are the issues Nurses need to consider when supporting this person?</b></p> <ul style="list-style-type: none"> <li>▪ pre- and post-operative care</li> <li>▪ maintenance and replacement of tracheostomy tube</li> <li>▪ cuff pressure (if cuffed)</li> <li>▪ maintenance and safe handling of tracheostomy equipment</li> <li>▪ maintenance and replacement of non-invasive equipment</li> <li>▪ humidification</li> <li>▪ suction</li> <li>▪ back up manual ventilation</li> <li>▪ stoma care</li> <li>▪ oral care</li> <li>▪ positioning</li> <li>▪ comfort of ties and masks</li> <li>▪ plan for dislodged tube</li> <li>▪ regular checks of ventilation machines</li> <li>▪ settings on ventilation machines</li> <li>▪ financial assistance for specialised equipment through FACS's AIDAS program or Enable's Home Respiratory Program</li> </ul> <p>(Clark &amp; Gates, 2006; Davis et al, 2013; Pearce &amp; Prigmore, 2012; Therapeutic Guidelines, 2012; Wallis, 2009)</p>		
<b>TYPE 2 DIABETES</b>		
<p><b>What are the issues Nurses need to consider when supporting this person?</b></p> <ul style="list-style-type: none"> <li>▪ risks, e.g., weight, statins, testosterone deficiency</li> <li>▪ possible signs, e.g., excessive drinking, frequent urination</li> <li>▪ diet (low glycaemic index)</li> <li>▪ exercise</li> <li>▪ sleep</li> <li>▪ medication and interactions</li> <li>▪ blood sugar levels</li> <li>▪ foot care</li> <li>▪ infection control</li> </ul> <p>(Phillips &amp; Gadsby, 2012; Rey-Conde &amp; Lennox, 2007; Therapeutic Guidelines, 2012)</p> <p>The Nurse collaborates with the GP, Dietitian and Physiotherapist to prevent or identify Diabetes Type 2 or manage the threats to health from a diagnosis of Diabetes Type 2. The Nurse may consult with the local Diabetes Nurse Educator and a referral to an Endocrinologist and a Podiatrist may be warranted.</p>		

Questions / Answers	Comments	Meets Requirements (WPSP)
<b>MANAGEMENT OF BOWEL PROBLEMS</b>		
<p><b><i>Faecal Incontinence</i></b>  <b>What are the issues Nurses need to consider when supporting this person?</b></p> <ul style="list-style-type: none"> <li>▪ diet and fluid intake</li> <li>▪ exercise</li> <li>▪ impact of medications</li> <li>▪ overflow diarrhoea</li> <li>▪ haemorrhoids</li> <li>▪ care of perineal area</li> <li>▪ suitable incontinence products through FACS's AIDAS program, the Federal Government's Continence Aids Payment Scheme (CAPS) and Enable NSW's Aids and Equipment Program</li> <li>▪ bowel habit training</li> <li>▪ regular enemas</li> <li>▪ sacral nerve stimulation</li> </ul> <p>The management of faecal incontinence in this population is usually with incontinence products. The Nurse may consult with an Incontinence Nurse Advisor</p>		
<p><b><i>Constipation</i></b>  <b>What are the issues Nurses need to consider when supporting this person?</b></p> <ul style="list-style-type: none"> <li>▪ record of bowel motions</li> <li>▪ method of reporting</li> <li>▪ strategies to maintain regularity, including toileting times</li> <li>▪ frequency, size and consistency of bowel motions</li> <li>▪ types of aperients and rectal medications</li> <li>▪ impact of other medications</li> <li>▪ examination per rectum</li> <li>▪ haemorrhoids</li> <li>▪ bowel sounds</li> <li>▪ abdominal palpation</li> <li>▪ abdominal x-ray</li> <li>▪ care of perineal area</li> <li>▪ suitable incontinence products through FACS's AIDAS program, the Federal Government's Continence Aids Payment Scheme (CAPS) and Enable NSW's Aids and Equipment Program.</li> </ul> <p>While there is no clear evidence for fibre, fluids and exercise for the management of constipation, this is considered best practice. The Nurse may collaborate with the Dietitian regarding fibre and fluids, with the Physiotherapist regarding exercise, and with the GP regarding suitable medications.</p>		



Questions / Answers	Comments	Meets Requirements (WPSP)
<b>MANAGEMENT OF BLADDER PROBLEMS</b>		
<p><b>Urinary Incontinence</b></p> <p>The management of urinary incontinence for people with intellectual disability is usually with incontinence products. Some interventions may be useful in the prevention of urinary incontinence.</p> <p>The Nurse may consult with an Incontinence Nurse Advisor and considers:</p> <ul style="list-style-type: none"> <li>▪ alcohol and caffeine intake</li> <li>▪ times of fluid intake</li> <li>▪ bladder training, e.g., Kegel exercises, toilet timing</li> <li>▪ medical treatments, e.g., pessary, Botox, collagen, sacral nerve stimulation</li> <li>▪ care of perineal area</li> <li>▪ suitable incontinence products through FACS's AIDAS program, the Federal Government's Continence Aids Payment Scheme (CAPS) and Enable NSW's Aids and Equipment Program</li> </ul> <p>The Nurse manages bladder problems in collaboration with the GP to prevent threats to health from incontinence and infection and may consult an Incontinence Nurse Advisor, a Urology Nurse or a Behaviour Specialist.</p>		
<p><b>Urinary Tract Infections</b></p> <p>The role of the Nurse related to urinary tract infections is in prevention, identification and treatment in consultation with the GP.</p> <p>The Nurse considers:</p> <ul style="list-style-type: none"> <li>▪ training for females on toilet hygiene</li> <li>▪ urinary alkalisers, eg, cranberry, Ural</li> <li>▪ prophylactic antibiotics for underlying abnormalities, eg, vesico-ureteric reflux</li> <li>▪ signs such as irritability, crying, going off food, vomiting, frequency, difficulty with micturition, odour, discolouration, fever</li> <li>▪ symptoms such as stinging and burning, abdominal pain</li> <li>▪ urinalysis</li> <li>▪ urine sample for culture</li> <li>▪ antibiotics</li> </ul>		

Questions / Answers	Comments	Meets Requirements (WPSP)
<b>SEIZURE MANAGEMENT</b>		
<p>The Nurse considers:</p> <ul style="list-style-type: none"> <li>▪ regular review with Neurologist</li> <li>▪ record of AEDs used</li> <li>▪ record of seizures</li> <li>▪ epilepsy management plan</li> <li>▪ blood tests required</li> <li>▪ regular bone mineral density</li> <li>▪ adverse reactions to AEDs, eg, drowsiness, aggression, gingivitis, drop in Vitamin D, osteoporosis, altered liver function.</li> <li>▪ changes in frequency, duration or type of seizures</li> <li>▪ Sudden unexpected death in epilepsy (SUDEP)</li> <li>▪ triggers, eg, strobe lights, alcohol, dehydration, pain, fever, menstruation, constipation, other medications (eg, OCP), sleep disturbance</li> <li>▪ safety, eg, water, falls</li> <li>▪ bed seizure alarm</li> <li>▪ medical alert bracelet</li> <li>▪ first aid</li> <li>▪ emergency</li> <li>▪ recovery</li> <li>▪ follow up of unusual seizure activity, eg, review with Neurologist, change to epilepsy management plan</li> <li>▪ ketogenic diet</li> </ul> <p>Seizures may occur with conditions other than epilepsy, eg, hypo- or hyper-glycaemia, ventral shunt blockage. If there is no history of epilepsy, it is best to consider other alternative explanations for seizures. (Codling &amp; MacDonald, 2009; Ilchef, 2013; Therapeutic Guidelines, 2012)</p> <p>The primary aim of treatment is for the person to become seizure-free. Most people in this population will have seen a neurologist. They have most likely had an encephalogram (EEG) and have been prescribed anti-epileptic drugs (AEDs).</p>		
<b>AUTISM SPECTRUM DISORDERS (ASD)</b>		
<p><b>Autism Spectrum Disorders are characterised by are a group of developmental conditions Please list the 4 main areas:</b></p> <ul style="list-style-type: none"> <li>▪ problems with communication – comprehension is limited and literal; expressive language is repetitive, echolalic and stereotyped, with lack of reciprocal conversation (chat)</li> <li>▪ problems with social development and interaction – reciprocal relationships and</li> </ul>		

Questions / Answers	Comments	Meets Requirements (WPSP)
<ul style="list-style-type: none"> <li>empathy are impaired</li> <li>▪ restricted and repetitive interests and behaviour – routines are important and there is resistance to change</li> <li>▪ anxiety and compulsions.</li> </ul>		
<p><b>List some of the health issues associated with autism? What is your role in managing these issues?</b></p> <ul style="list-style-type: none"> <li>▪ anxiety</li> <li>▪ chronic gastrointestinal problems – constipation, bloating, abdominal pain, nausea, diarrhoea</li> <li>▪ atypical sensory responses – heightened responses to light, sound, textures, taste, smell</li> <li>▪ seizures</li> </ul> <p>(Centre for Genetics Education, 2013; Howlin, 2002)</p>		
<b>CEREBRAL PALSY</b>		
<p><b>Cerebral palsy can be classified according to 3 areas? Please list the 3 :</b></p> <ul style="list-style-type: none"> <li>▪ <b>type</b> of motor disorder (the way the body is affected) – hypertonic (spastic), hypotonic, athetoid, dyskinetic, ataxic, mixed</li> <li>▪ <b>distribution</b> of motor disorder (where the body is affected) – quadriplegic, diplegic, hemiplegic</li> <li>▪ <b>severity</b> of motor disorder – categorised on a scale of GMFCS I-V by using the Gross Motor Function Classification System (GMFCS).</li> </ul>		
<p><b>List 4 of the Health issues associated with a person who has cerebral palsy?</b></p> <ul style="list-style-type: none"> <li>▪ sensory impairments (visual, hearing, touch)</li> <li>▪ epilepsy</li> <li>▪ neuromuscular problems</li> <li>▪ skeletal deformities</li> <li>▪ osteoporosis</li> <li>▪ incontinence</li> <li>▪ voiding dysfunction</li> <li>▪ constipation</li> <li>▪ skin breakdown</li> <li>▪ pain</li> <li>▪ depression</li> <li>▪ dysphagia</li> <li>▪ eating and drinking difficulties</li> <li>▪ malnutrition</li> <li>▪ recurrent aspiration</li> <li>▪ gastro-oesophageal reflux disease (GORD)</li> <li>▪ Barrett's oesophagus</li> <li>▪ gastric bleeding/anaemia</li> <li>▪ poor peripheral circulation</li> <li>▪ recurrent chest infections</li> <li>▪ chronic lung disease</li> <li>▪ dental problems</li> </ul> <p>(CDDH, 2013; CDDS, 2006, Cerebral Palsy Alliance, 2013)</p>		

Questions / Answers	Comments	Meets Requirements (WPSP)
<b>DOWN SYNDROME</b>		
<p><b>Identify 4 health issues associated with Down Syndrome that a nurse should be aware of:</b></p> <ul style="list-style-type: none"> <li>▪ visual impairments (including cataracts)</li> <li>▪ hearing impairments</li> <li>▪ hypothyroidism</li> <li>▪ epilepsy</li> <li>▪ congenital heart defects</li> <li>▪ hypotonia</li> <li>▪ cervical spine problems (atlanto-axial instability)</li> <li>▪ sleep apnoea</li> <li>▪ respiratory infections</li> <li>▪ dental/oral problems</li> <li>▪ skin disorders – eczema, alopecia</li> <li>▪ blood dyscrasias</li> <li>▪ leukaemia</li> <li>▪ immune system problems – increased infections, diabetes, coeliac disease</li> <li>▪ GORD</li> <li>▪ constipation</li> <li>▪ fitness and weight problems</li> <li>▪ anxiety and depression</li> <li>▪ early onset dementia (Alzheimer's)</li> </ul> <p>(CDDS, 2006; Centre for Genetics Education, 2013; Tracy, 2011)</p>		

**Case Discussion / Examples.**

*Don't forget to include the elements that the nurse is looking for in each sample.*

- *Case discussion / examples must have been completed within the previous 12 months.*
- *Case discussion / examples are acceptable if completed in collaboration with another nurse. Nurse can discuss the participant's level of contribution with them to enable sign off.*

Work Practice Sample Required	Comments	Meets requirements (WPSP)
<p><b>Does the person with an intellectual disability need to give consent even though they are non verbal?</b></p> <p><i>Remember:</i> nothing can be done without <b>consent</b> from person with intellectual disability or substitute consent from 'person responsible'. (See: your organisation's Decision Making and Consent Policy and Procedures).</p>		
<p><b>Discuss 2 cases you have been involved with who have a complex health conditions? Provide examples of what these conditions were and what role did you play?</b></p>		

**Observations:**

*Don't forget to include the elements that the nurse is looking for during the observation.*

*Observations must have been conducted within the previous 12 months.*

Observation Description	Comments	Meets Requirements (WPSP)
<p><b>The nurse has demonstrated a clear understanding of the complexities of supporting a person with a disability?</b></p> <ul style="list-style-type: none"><li>• Questions used to clarify responses and elicit more information.</li><li>• Notes are taken during or after the meeting.</li><li>• The ability to develop a comprehensive health care plan after consultation.</li><li>• The ability to provide accurate information via documentation,</li><li>• The ability to confirm correct information.</li></ul> <p>Recorded responses/notes match the nurse's notes</p> <p><i>Impressions of the nurse and clients interactions during the assessment, context and respondent are discussed with WPSP following the interview.</i></p>		
<p><b>Was there good participation and outcomes observed during the consultation? Provide an example where it applies.</b></p> <ol style="list-style-type: none"><li>1. The person had a strong understanding of the principles around the health care needs.</li><li>2. The Health Practitioner had a good rapport with the person and other stakeholders.</li></ol>		

**Date all work above signed off by WPSP:**

**I confirm that all requirements have been met for this core standard.**

**Signed:**

**Name:**

**Position:**

**Date:**

## Reference and Further Resources

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