

## MND Advanced Clinical Nurse Specialist Pillars of Practice Competencies – Band 7

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### Aim of this document

The Motor Neurone Disease Clinical Nurse Specialist competencies have been developed to provide guidance and structure to Advanced Clinical Nurse Specialists and their Line Managers to create a co-ordinated, consistent and sustainable care delivery to patients affected by MND in Scotland.

This document has been created in consultation and collaboration by the MND Nurse Consultant and all the current MND Nurse Specialists in Scotland. The document has been systematically reviewed and developed in accordance with the Workforce Planning Guidance of The Scottish Government National Health and Workforce Plan – Nursing and Midwifery defining roles specialist competencies for MND. The working group have also looked at what makes a MND CNS, cross referencing the NICE guidelines (NICE, 2016), the Key Performance Indicators as directed by The Scottish MND CNS Consortium and applied this to The Four Pillars of Advanced Practice, NES. The specialist competencies will allow nurses working at Band 7 in the MND speciality to deliver and sustain an extremely high standard of nursing care to those diagnosed, living and dying with MND.

### Objectives

- The document will be reviewed as part of the initial induction of the Advanced Clinical Nurse Specialist into their post
- The document will be reviewed on a regular basis as part of the post holder's CPD and Appraisal
- Learning needs will be identified through this document and appropriate measures will be put in place to ensure the post holder meets the desired competency.

### The 4 Pillars of Practice:

- 1) Advanced clinical skills
- 1). Leadership
- 2). Facilitation of learning
- 3). Research



### Training courses and competency certification

- 1) ALS Functional Rating Scale (ALSFRS-R): a validated scale for numerically scoring ALS patients (on-line training and certification)
- 2) Edinburgh Cognitive ALS Screen (ECAS): a validated rapid screen for assessing cognition and behaviour changes in those with MND (on-line training and certification)
- 3) King's Staging: a rapid assessment to stage patients with ALS, clinically useful in noting decline (on-line training)
- 4) Ante-mortem brain and spinal cord consent (attend session at R&D update)
- 5) Authorisation to obtain post-mortem consent (attend post-mortem examination and attain certification from professor of neuro-pathology)
- 6) Induction to CARE-MND (accreditation and noting on delegation log)
- 7) Good Clinical Practice (GCP) certification (training available both local and on-line)

### Abbreviations List

ALSFRS-R - ALS Functional Rating Scale  
ACP – Advance Care Planning  
AHP – Allied Health Professionals  
ALS – Amyotrophic Lateral Sclerosis  
CPD – Continued Professional Development  
DNACPR – Do Not Attempt CPR  
ECAS - Edinburgh Cognitive ALS Screen  
FTD – Frontotemporal Dementia  
GCP – Good Clinical Practice  
KPIs – Key Performance Indicators  
LPA – Lasting Power of Attorney  
MDT – Multidisciplinary Team  
MND – Motor Neuron Disease  
NIV – Non-Invasive Ventilation  
PLS – Primary Lateral Sclerosis  
PMS – Progressive Muscular Atrophy



SLT – Speech and Language Therapy

1- Advanced Clinical Skills

Pillar Advanced clinical Practice	Performance Indicators	Self-assessment (1-5)	Action Plan	Supervisor assessment	Evidence of assessment
Complex needs of patients and their families	Clinical expert demonstrating comprehensive knowledge of MND and the complex and variable disease trajectories: <ul style="list-style-type: none"> <li>- Different subtypes (ALS, PLS, PMA)</li> <li>- Variable and complex disease progression</li> </ul>				
	Demonstrates competence in prioritising, escalating, de-escalating, providing self-help or management advice and/or referring timeously for treatment/assessment within the clinical context of their role.				
	Demonstrates ability to undertake a comprehensive focused person-centred holistic assessment of the patient and actively involves the patient and their families/carers/loved ones.				



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	<p>This includes the following areas:</p> <ul style="list-style-type: none"> <li>- Cognition screening</li> <li>- Respiratory assessments</li> <li>- Nutrition, hydration and weight assessments</li> <li>- Anticipatory care planning a (DNACPR, DS1500, Continuing Power of Attorney for health and wealth attorney)</li> <li>- Right to Speech Act and communication Speech and language therapy referral</li> <li>- Muscle management and movement</li> <li>- Emotional lability</li> <li>- Carer Burden</li> </ul>				
	<p>Has responsibility to reflect upon and review own decisions in relation to care management and the effectiveness of care programmes. Utilises freedom, accountability and authority within a speciality, taking account the value to the patient, to request, and apply, where indicated:</p> <ul style="list-style-type: none"> <li>-Diagnostic test/investigations</li> </ul>				



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	<ul style="list-style-type: none"> <li>-Multidisciplinary/agency health and social services assessments</li> <li>-Application of protective and safe guarding legislation</li> <li>- Dealing with issues of consent and capacity, recognising existing legal requirements</li> <li>- Acknowledgement of Continuing Power of Attorney for health and wealth</li> <li>- Withdrawal of consent to take part in research</li> </ul>				
	<p>Is involved in assessing, diagnosing and interpreting acute and chronic patient's symptoms and investigations. Analyses findings from various multi-element assessments, tests and investigations. Coordinates effectively with the multi-disciplinary team (Respiratory, Nutrition, Neuropsychology, Speech &amp; Language...)</p>				
	<p>Accountable and responsible for making decisions and clinical judgements in relation to care management underpinned by specialist knowledge and expertise. Undertakes an accurate assessment of treatment side effect and</p>				



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	<p>applies relevant treatment knowledge to the following:</p> <ul style="list-style-type: none"> <li>- Riluzole counselling</li> <li>- Gastrostomy (eg: infection control, pain management and sepsis) NIV (eg: withdrawal issues and dying with NIV)</li> <li>- Secretion management (escalation of medications up to Botox)</li> <li>- Other medications (eg: pain management)</li> <li>- Trial drugs</li> </ul>				
	<p>Critically reviews the evidence base for nursing management of MND symptoms and treatment side effects.</p>				
	<p>Accountable and responsible for decisions relating to management, standards and quality of clinical practice, demonstrating knowledge about the safe administration of therapies and the nursing interventions necessary to manage an adverse reaction to treatment:</p> <ul style="list-style-type: none"> <li>- Initiation of NIV, breath stacking, Cough Assist</li> </ul>				





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	<ul style="list-style-type: none"> <li>- Oxygen therapy in dyspnoeic patients</li> </ul>				
	<p>Develops implements and evaluates strategies to improve practice in nurse led assessment. Monitors the patient's health status for signs and symptoms of deterioration and takes steps to document, intervene or refer appropriately. Examples of red flags include:</p> <ul style="list-style-type: none"> <li>- Time from onset to diagnosis</li> <li>- Site of onset</li> <li>- Genetics</li> <li>- Cognitive profile</li> <li>- Weight loss/BMI</li> <li>- Mobility, falls</li> <li>- Strength</li> <li>- Bulbar symptoms</li> <li>- ALSFRS</li> <li>- Sleep studies</li> </ul>				
	<p>Implements and critically evaluates the range of evidence-based interventions to manage the complex, multiple needs of MND patients and their families</p>				
	<p>Clinical expert who is responsible for developing and implementing highly specialised, patient centred care</p>				



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	<p>programmes to meet physical and psychological need, enabling people to develop effective coping mechanisms and self care strategies. Works in partnership with the patient to manage symptoms of MND and subsequent consequences of MND treatment. Engage with patient and families in establishing goals of patients.</p>				
	<p>Demonstrates knowledge of the implications of chronic illness and long-term survivorship in those affected by MND such as increased use and requirement for mechanical aids, catheter, feeding tube, respiratory support. Considers the ethics of treatment withdrawal.</p>				
	<p>Works in collaboration with MND MDT in delivering a high quality service which is evidence based. Facilitates this by providing expert clinical knowledge, skills advice and information Describes the principles of palliative-rehabilitation, self-management and lifestyle interventions for improving quality of life in those affected by MND. Considers the following options for patients:</p>				



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	<ul style="list-style-type: none"> <li>- Hospice day services</li> <li>- Day therapies</li> <li>- Dementia care</li> <li>- Lifestyle choices</li> <li>- Mental health support</li> <li>- Engagement in support groups</li> <li>- Third sector involvement</li> </ul>				
	<p>Considers the need for environmental adaptations and planning ahead for these. Is able to discuss triaging future needs and develop a prediction of course of decline and plan in advance accordingly.</p>				
	<p>Understands the importance of medicine management and the dangers of non-adherence in patients. Understanding of different routes of medication administration (oral, PEG, SC). Discusses the pros and cons of symptomatic control discuss importance on compliance of secretion medicine. Discusses the role of early intervention of opiates in the management of breathlessness.</p>				
	<p>Highly developed interpersonal and negotiating skills required for continuous communication with a wide</p>				



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	<p>range of health and social care workers at both strategic and operational levels. Demonstrates an understanding of the importance of seamless transitions between the acute and home care, palliative and end-of-life care. Considers advance directives to refuse treatment and the ethics of NIV and or gastrostomy withdrawal and the impact this will have on life expectancy.</p>				
	<p>Recognises the differing care needs of patients from disadvantaged or vulnerable groups as well as those with a deteriorating cognitive, physical or communication ability.</p>				
Advanced Communication Skills	<p>Utilises sensitive and empathetic communication skills in conjunction with specialist knowledge. Considers their own attitudes, beliefs and behaviours towards end of life care. -Considers the potential emotional distress of patients - Include families/carers in discussions on end of life care</p>				
	<p>Considers ethical issues around genetic testing, familiar MND and the wishes of patients and their families.</p>				



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	<p>Uses evidence-based strategies to deal with communication issues for patients with cognitive deterioration in MND and addresses the needs of the family and carer in understanding of these symptoms and developing support mechanisms</p>				
	<p>Assess the supportive care needs of patients and their families, and be able to refer to appropriate support services such as MND support groups and charities, demonstrating local knowledge of these.</p>				
	<p>Reflects on communication skills and considers theories of good communication in supporting the individual and family affected by MND. Considers the fact that different patients will require different approaches.</p>				
	<p>Differentiates between the different roles information technology can have in improving care delivery and remote health management. Is familiar with Attend Anywhere for telehealth, the electronic CARE-MND platform, as well as apps for remote NIV adjusting and monitoring.</p>				



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	Assesses the ongoing and changing needs of the patient and family members for education, evaluating the individual's understanding of advice and information over time.				
	Demonstrates the use of a range of advanced communication skills/techniques to promote wellbeing in a patient eg: counselling skills, challenging behaviour and active listening.				
	Recognises the ethical and legal dilemmas as an advocate in providing informed consent and support for patients, in particular when dealing with patients with cognitive decline or FTD.				
Non-medical Prescribing	Undertakes an accredited course in non-medical prescribing as per local health board requirements				
	Adheres to Prescribing Competency Framework (Royal Pharmaceutical Society/NICE, 2016).				
	Demonstrates knowledge in educating patients regarding medications.				
	Engages in regular reflection and clinical supervision regarding their practice of non-medical prescribing.				



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Site Specific advanced Clinical Skills	Determines the frequency of regular review in order to manage symptoms and assess therapeutic intervention response within their speciality which may be across a range of care settings and over a prolonged period of time.				
	Advanced practitioner who actively participates in working collaboratively across healthcare boundaries demonstrating the application of highly specialist knowledge of the disease along with understanding and skills to manage or prevent symptoms and psycho-social challenges secondary to the disease/speciality/treatment.				
	Triage of patients presenting with unscheduled problems by telephone. Demonstrates knowledge on how to admit and discharge from their specialist area.				
	Act as patient advocate assisting in ethical aspects of management and treatment. Provides specialist advice and support in partnership with patients and their families throughout the care pathway from pre-diagnosis/diagnosis, through complex treatment to death.				



	<p>Acts as an expert clinical advisor, resource or educator to other health care professionals and regularly updates their knowledge and evidence-base to ensure appropriate clinical skills and competencies related to their speciality are used effectively and that clinical governance standards are maintained.</p>				
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2- Leadership

<b>Pillar:</b>  <b>Leadership</b>	<b>Performance Indicators</b>	<b>Self-assessment (1-5)</b>	<b>Action Plan</b>	<b>Supervisor Review (1-5)</b>	<b>Evidence of Achievement</b>
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Teamwork and Development	Establishes leads and implements strong and effective leadership across professional and organisational teams. This includes coordinating with the wider multidisciplinary team and across different Health Boards, noting the need for rapid access to these teams.				
	Provides leadership in collaborating with multi professional, multi-agency bodies to maintain networks and partnerships.				
	Applies appropriate leadership and management strategies in their practice and evaluates the impact of these upon others in the MND team and AHP workforce.				
	Demonstrates the ability to plan, allocate, coordinate and evaluate the use of health care resources in an appropriate manner when providing care to patients and their families.				
	To act as a role model, functioning in a variety of role dimensions (educator, coach, advocate, advanced care provider etc).				



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	Actively participates in implementing change in practice, offering expert evidence based informed advice to others on therapeutic interventions, practice and service development to better meet the needs of those accessing the service.				
	Demonstrates how to engage the team to provide collaborative, compassionate person centred care throughout service delivery. Auditing of patient care through the national database (CARE-MND), which enables a standardised approach to MND care in Scotland.				
Professional and organisational leadership	Provides leadership in the implementation and evaluation of quality standards, drawing from the NICE MND guidelines (NICE, 2016).				
	Reflects on leadership styles and how different models of clinical leadership can impact disease management.				
	Actively participates and encourages involvement of service users to influence and improve person-centred care, noting and understanding the rapid disease				



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	<p>trajectory and the requirement for some services to reach the patient in their home environment and the delivery of a flexible health care system.</p>				
	<p>Actively contributes to a variety of professional networks, this includes: MND team meetings (quarterly), ALS International Conferences, European ALS network meetings, (ENCALS) ; MND Scotland, British Association of Neurological Nursing, local clinical networks, palliative care networks.</p>				
	<p>Informs the strategic direction and leads on change to service delivery. Implement redesign initiatives to drive service development and delivery by NHS boards and based on the KPIs drawn from the Annual CARE-MND Audit.</p>				
	<p>Assesses risk and implements appropriate risk management strategies in order to promote patient wellbeing and safety in their practice area.</p>				



3- Facilitation of Learning

<b>Pillar:</b>  <b>Facilitation of Learning</b>	<b>Performance Indicators</b>	<b>Self-Assessment (1-5)</b>	<b>Action Plan</b>	<b>Supervisor review (1-5)</b>	<b>Evidence of Achievement</b>
Learning, Teaching and Assessment	Develops and delivers educational activities, applying the principles of learning; monitoring and evaluating effectiveness of educational strategies used to achieve the following: <ul style="list-style-type: none"> <li>- Advanced communication skills amongst the AHP teams</li> <li>- Understanding of the variability of the complexities of MND and demonstrate how these complexities may interact with the delivery of care</li> <li>- Understanding of disease impact on family &amp; health professionals</li> </ul>				



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	- Presenting at local, regional and international conferences				
	Demonstrates evidence of their own CPD by identifying, analysing, prioritising, negotiating own training and development needs.				
	Reflects on practice and supports reflection in others: -using appropriate reflective tools -participating in clinical supervision -facilitating feedback				
Creating the learning environment	Creates an effective learning environment that ensures learning opportunities for staff and students: -Create a positive culture of learning -Leads/participates in educational audit and learning needs analysis				
	Contributes to the development and delivery of accredited and non-accredited education				
	In the course of completing/planned to complete an MSc in MND				
	Acts as role model and expert resource for multi professional and multi-agency groups facilitating access to a range of clinical support strategies like				



	mentoring (colleagues and students), clinical supervision, and coaching.				
	Participates in audits of teaching to improve performance.				

4- Research

<b>Pillar</b>	<b>Performance Indicators</b>	<b>Self-assessment (1-5)</b>	<b>Action Plan</b>	<b>Supervisor assessment</b>	<b>Evidence of achievement</b>
<b>Research</b>					
Evidence into practice	Actively participates and promotes an evidence-based approach to disease management and applies research findings to improve practice. Promotes and recruits to the following MND studies: - MND-CARE database				



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	<ul style="list-style-type: none"> <li>- MND SMART trial</li> <li>- Scottish DNA and Brain Bank</li> </ul>				
	<p>Accreditation at Good Clinical Practice (GCP). This can be obtained on-line or by attending a course.</p>				
	<p>Attendance of the annual Research and Development session on MND at University of Edinburgh (certificate of attendance issued).</p>				
	<p>Advises on the implications of interventions on the eligibility for MND clinical trials by having in depth knowledge of the exclusion and inclusion criteria, working within an ethical and legal framework, utilising defined policies and procedures, standards and protocols</p>				
	<p>Actively seeks the views of service users to improve the MND service and healthcare experience for the individual.</p>				
	<p>Uses specialist knowledge to contribute to the development of evidence-based policies and procedures and practice development.</p>				



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	Describes the principles of clinical trials and the contribution which nurses make to the safe conduct of multidisciplinary research.				
	Demonstrates an ability to participate in clinical trials as part of a multi-professional team, maintaining a good working relationship with the National MND Research Teams. Additionally supports more junior colleagues in this role.				
	Analyses and critiques the latest MND research and applies this to service development.				
	Actively participates in undertaking focused and detailed clinical audit and evaluation of service.				
	Monitors quality of own practice and identifies gaps in service by review of the local Health Board Audit produced from CARE-MND annually. Participates in continuous audits and research into quality improvement.				





## References

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