Model of Care Document for Specialised Weaning Units

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Contents

Within this document are quotes from patients and families about their time spent on critical care and on a specialised weaning unit. The full text can also be found in appendices 1 and 2.

Summary of key points

- 5-10% of critically ill patients require respiratory support for more than 21 days and utilise up to 25% of critical care capacity
- Care of such patients is best delivered by a multi-professional team on a Specialist Weaning Unit which is co-located with a complex home ventilation service
- Patients will usually be tracheostomised and have required Invasive Mechanical Ventilation for at least 3 weeks, though some patient groups will benefit from earlier involvement of the SWU such as patients with pre-existing neuromuscular, respiratory or chest-wall disorders
- Patients will have no ongoing requirement for acute non-respiratory organ support
- SWUs should have a clear place within the overall management structure of a healthcare organisation
- There should be designated operational, medical, nursing, pharmacy and Allied Health Professional (AHP) clinical leads for the unit
- Each SWU should have an operational policy setting out admission and discharge criteria, workforce and equipment requirements and patient pathways
- SWUs will be run from a complex home ventilation service. Within an organisation, this may be part of Respiratory Medicine or Critical Care and there must be close clinical collaboration between the two specialities
- Access to critical care in emergencies must be available 24/7
- Patient and family-centred research and quality improvement activities should be embedded within SWU core activities with involvement from the multi-professional team
- To further inform the evidence base, a SWU core dataset and an end user informed (patient, family members, and multi-professional team) core outcome set should be developed
- Given the relatively small patient numbers managed annually at each SWU, we recommend a collaborative approach to research and quality improvement activities across all UK SWUs
- A twice daily safety briefing using an appropriate safety checklist (see Appendix 2) should be usual practice
- A robust monthly morbidity and mortality (M&M) process must be in place including all inpatient deaths on the SWU and following discharge to other hospital wards or critical care units
- Patients who are weaning from mechanical ventilation and meet the criteria for admission to a SWU should have their care delivered within a designated ward area
- A full multiprofessional team will include medical, nursing, physiotherapy, dietetics, occupational therapy, pharmacy, psychology and speech and language therapy
- The multiprofessional team will have extensive experience in acute and long term ventilation
- Workforce provision should reflect local requirements and where available, national guidance for staffing should be followed
- Palliative care input should be available seven days a week
- SWUs should provide support to critical care units across a critical care network and beyond. This may include: remote advice on weaning strategies and rehabilitation and on-site assessment at local ICUs as well as transfer to the SWU

- Transfer to the SWU for a period of assessment may also be appropriate and the length of a SWU admission for assessment should be defined prior to acceptance and transfer
- The assessment of patients with complex weaning failure requires a comprehensive review from the SWU multi-professional team
- SWUs may need to repatriate patients who cannot be weaned back to the referring hospital and commissioning pathways should be in place to facilitate this along with local formal agreement to prioritise repatriation transfers within 48 hours
- Local treatment, monitoring and equipment protocols will be developed by SWUs
- Complex discharge planning requires a multi-professional team, a lead for the discharge and close liaison with the complex home ventilation service for patients discharged with ongoing requirements for ventilatory support
- Following discharge there must be clear protocols for readmission and advice for patients including clinical and equipment related issues
- If discharge is to home or an intermediate care facility, the patient's GP practice must receive a detailed handover of the events during hospital admission, what complications may be anticipated and a list of medications including changes during hospital admission
- Follow up should involve the SWU multi-professional team where patients are discussed and a follow up clinic appointment arranged based on individual patient need

Introduction

> *"Intensive care saved my life but broke my spirit."*
>
> *Once I was out of danger and left on a breathing machine because they said that I could not breathe on my own, I felt forgotten.*
>
> *"I became the woman in the side room who kept "failing"... to come off the breathing machine."*

Purpose

Specialised Weaning Units (SWUs) enable an effective step down from critical care for adult patients who continue to require invasive mechanical ventilation (IMV) following prolonged admission. Their purpose is to achieve weaning to the least invasive method of respiratory support. Weaning success is defined as complete liberation from IMV for seven consecutive days, though may include a continued requirement for nocturnal non-invasive ventilation (NIV) (1). A significant proportion of patients continue to require long-term NIV after weaning from prolonged IMV. A

small percentage of patients (10-20%) are unable to wean from invasive support via a tracheostomy and require ongoing community support (2,3). This is best delivered via such SWUs, which are co-located within Complex Home Ventilation services in the UK.

Rationale

Studies have demonstrated that 5-10% of patients will fail to wean from IMV within three weeks but account for more than 25% of critical care bed occupancy because of the prolonged duration of stay (4,5). This would equate to 50-100/1000 patients who will benefit from discussion with and advice from a SWU about weaning options.

For most patients, acute pathology is the greatest determinant of prognosis in the early critical care period. After approximately two weeks, underlying co-morbid conditions become a greater rate-limiting step in weaning from IMV (6). Mortality rates start to plateau, and surviving patients experience lesser degrees of organ failure requiring support and greater clinical stability. Successful unsupported breathing, however, depends on an adequate capacity to breathe (appropriate respiratory drive and neuromuscular function) in the context of a sufficiently low respiratory load (the work of breathing). The individual who cannot wean from IMV has an adverse imbalance between capacity and load. This usually arises from a combination of the acute precipitant, the overall impact of the critical illness (e.g. neuromyopathy), and chronic co-morbidity affecting the respiratory system (e.g. intrinsic lung disease, neuromuscular disorders).

An international consensus document concluded that there are key multi professional skills to achieve successful weaning following prolonged IMV, and that these are distinct from those available to most critical care units (7). This patient cohort are now very different from short-stay critical care patients and as such, optimal weaning approaches need to adapt to their needs. NIV provides an important bridge to unsupported breathing for a higher proportion of patients transferred to a SWU than those that remain in critical care. Careful tracheostomy management enables NIV to be used concurrently for periods of the day and night with the aim of decannulation. Following discharge, one UK regional SWU reported that 57% of patients continued to require long-term nocturnal NIV following successful tracheostomy decannulation (2). Reducing dependence on IMV builds patient confidence and promotes restoration of other functions such as speech and swallowing. Whilst respiratory capacity can improve with rehabilitation and time, some patients will continue to require long-term nocturnal NIV and a small percentage cannot wean from IMV and require complex community support. In the UK, SWUs are co-located within a regional Complex Home Ventilation service. The multi-professional approach and expertise of the home ventilation team align with the needs of the patient transferred for weaning from prolonged IMV.

There is good evidence that this structured specialist approach to the care of patients who require prolonged mechanical ventilation can improve outcomes. Longitudinal data from two UK centres show consistently high rates of hospital survival (84-91%) and discharge home (75%) following transfer (2,3). An international meta-analysis comparing different models of care showed that the SWU model achieved the highest survival and discharge home rates (8). Further, the SWU model achieved such outcomes at a lower cost to continued critical care (5) and improved critical care capacity for others.

Patient Cohort

Individuals who will benefit from transfer to a SWU include those who:

- Have required IMV for at least 3 weeks, including active attempts to wean from IMV for at least 7 days
- Are likely to wean to long-term nocturnal NIV. Patients with pre-existing neuromuscular, respiratory or chest-wall disorders will benefit from earlier discussion and transfer than 3 weeks. This may include discussion with an SWU prior to initiation of invasive ventilation
- Are usually tracheostomised at the time of transfer, though this is subject to individual case discussion and may include complex NIV
- Have no requirement for additional acute organ support (e.g. inotropes, vasopressors, cardiac mechanical devices, haemofiltration) at the time of transfer
- Have experienced sufficient resolution of the acute pathology that prompted critical care admission, and not be expected to require ongoing specialist non-respiratory intervention
- Have potential to wean or require establishment of long-term tracheostomy ventilation and complex discharge planning for community placement
- Have agreement from the patient and next of kin for transfer to SWU, or be in agreement with a best interest decision if the patient is not able to consent to transfer
- Are neurologically stable; however, patients with mild delirium managed without intravenous agents and patients with significant brain injury who may nonetheless benefit from transfer can be considered following discussion with the SWU

Exclusion criteria

Individuals who are not suitable/appropriate for admission to a SWU include:

- Ongoing clinical instability or requirement for other organ support
- FiO_2 requirements at 40% or above should be considered on an individual basis

- Individuals for whom long-term ventilation is not in their best interests on the grounds of futility (for example, very poor limited prognosis due to associated or underlying disease severity). This decision should usually only be made after discussion with the SWU

- Individuals with high cervical spine injuries (managed within a separate specialist spinal injury service)

- Paediatric population

Governance

Management

SWUs should have a clear place within the overall management structure of a healthcare organisation.

There should be designated operational, medical, nursing, pharmacy and Allied Health Professional (AHP) clinical leads for the unit and regular meetings should take place between the SWU operational and clinical leads.

Creation of a separate SWU line management structure is recommended to facilitate day-to-day operational management. There should be clear lines of reporting for the SWUs within a directorate or divisional management structure of the healthcare organisation. Larger SWUs should function as a separate business unit.

The healthcare organisation will be accountable for ensuring that the SWU meets local and national service standards; supports workforce recruitment, retention and training; and is responsible for establishing and maintaining physical infrastructure (including estates, facilities, equipment and consumables).

SWUs should be geographically co-located with Complex Home Ventilation services within the same healthcare organisation.

Each SWU should have an operational policy setting out admission and discharge criteria, workforce and equipment requirements and patient pathways.

Commissioning arrangements for SWUs is beyond the scope of this document and local business plans should be developed which are informed by this guidance.

Interdependence with Other Services

SWUs will be run from a complex home ventilation service. Within an organisation, this may be part of Respiratory Medicine or Critical Care. Irrespective of the divisional management, there must be close clinical collaboration between the two specialities. Access to critical care in emergencies must be available 24/7.

Other services which must be immediately accessible are radiology, laboratory sciences, pharmacy, lung function department, ventilation technicians and electronics & medical engineering teams.

Research and Quality Improvement

Patient and family-centred research and quality improvement activities should be embedded within SWU core activities with involvement from the multi-professional team. Research and quality improvement activities should be directed by a nominated research and quality improvement lead(s) with access to research delivery team support (5 days/week). This leadership will coordinate activities including participation in network research via the National Institute of Healthcare Research Clinical Research Network (or similar). Essential components of quality improvement include sufficient resource and time, continuous data collection, and engagement with patients and carers. Engaging with patients and carers ensures that any iterative change is 'co-produced.'

To further inform the evidence base, a SWU core dataset and an end user informed (patient, family members, and multi-professional team) core outcome set should be developed. This should comprise immediate (e.g. weaning success, functional rehabilitation outcome, discharge home rates) and long-term clinical outcomes (e.g. quality of life, return to work, re-hospitalisation, survival). We also recommend a core outcome set of process outcomes (e.g. care plan co-development with the patient and family) with end user informed standardised quality indicators and tools focussed on actionable processes to improve care quality (appendix 3).

Given the relatively small patient numbers managed annually at each SWU, we recommend a collaborative approach to research and quality improvement activities across all UK SWUs. This includes peer review, participation in the collection of the core data set, use of a core outcome set, and quality indicators to allow benchmarking of care quality and outcomes across SWUs similar to participation in the Intensive Care National Audit & Research Centre Case Mix Programme. Standardised metrics would foster a multi-centre approach, whilst at the same time providing easier cross-unit interpretation of future single-centre projects. Future research and quality improvement initiatives relating to patients admitted to a SWU would benefit from a Research Priority Setting Exercise.

Safety

> *"From a personal perspective and as an example my son was unable to press a hospital buzzer due to muscle weakness and then lost his voice following tracheostomy so had no means of attracting the attention of staff."*

A tracheostomy management protocol must be in place including the emergency management of blockage or dislodgement (9, 10).

Monitoring should be centrally displayed with audible alarms.

Simulation training of all staff should be undertaken regularly including simulation of common emergencies such as those associated with tracheostomy.

Reasonable adjustments must be made to ensure the safety of patients who are unable to summon assistance in traditional ways such as using their voice or a call device especially patients with neurodisability.

A twice daily safety briefing using an appropriate safety checklist should be usual practice. This would include monitoring and planning the oxygen consumption of the SWU. These are routinely used in a theatre and critical care settings and can be adapted for use on a SWU. That in appendix 4 is an example of a safety checklist for a respiratory support unit which could be adapted for the needs of a SWU.

Mortality and morbidity review

A robust monthly morbidity and mortality (M&M) process must be in place including all inpatient deaths on the SWU and following discharge to other hospital wards or critical care units. This should be specific to the SWU.

Respiratory, home ventilation and critical care medicine should have an aligned process for such patients to ensure shared learning. There should be full representation from the extended multi-professional team and nurse leadership at these meetings with time in job plans to attend and contribute.

All critical incidents should be reported via local reporting guidelines and discussed regularly at M&M meetings.

A peer review process including external mortality reviews between SWUs should be encouraged.

Flexing for surges in demand

The COVID-19 pandemic has focussed the respiratory/critical care community on estates, infection control, personal protective equipment (PPE), oxygen usage and equipment set up for respiratory support. SWUs are not designed for routine repurposing for surges in critical care or respiratory ward demand. However, the COVID-19 pandemic and possibility of further requirements for surges in critical care capacity would dictate that they should be resourced and built to the same specification as critical care units. (11)

Service model

Estates/infection control

> *"From our perspective as parents of a young man with a deteriorating neuro muscular condition being able to stay with him throughout his hospital stay was for us non-negotiable."*
>
> *"Some facilities to support this such as a fold down bed by his side, showering facilities and tea/*

Patients who are weaning from mechanical ventilation and meet the criteria for admission to a SWU should have their care delivered within a designated ward area to ensure concentration of multi-professional team skills.

The number of SWU beds required will depend upon local requirements and will typically be embedded within a Complex Home Ventilation service ward area.

The central role families have in helping care for patients can be critical particularly in the care of young adults and those with neurodisability including learning disability. Areas for families to rest and sleep are important considerations for SWUs.

Specifications for the design of SWUs should be identical to existing specifications for the design of critical care units. (11) This would include supply of medical gases. Where a specialist weaning unit is part of a new build project, it is essential that the sustainability lead for the organisation is part of the project management team, to ensure alignment with organisational Green Plan objectives and national 'Delivering a Net Zero NHS' targets. (12) Achieving a minimum BREEAM standard of excellent (or equivalent) should be the goal for new builds. (13)

Detailed guidance on the design and standards of an isolation facility used for the treatment of patients with airborne pathogens has been developed by the Department of Health (14). SWUs should be designed to follow those principles, with rooms having either negative pressure ventilation or neutral pressure with a positive pressure ventilated lobby. Existing facilities can be converted to follow the same standards set out in the guidance with the focus being air exchange rate and pressure differentials to ensure rooms remain at negative pressure from the corridors.

Given the potentially high acuity of care required for SWU patients, a mixture of bays and cubicles may be more practicable to deliver care whilst retaining the ability to isolate patients. In this case the same design principles should be observed. Specific ventilation requirements are available (15). The overall ventilation quality of a unit will depend upon the air exchange rate, the flow of air and the filtration of air. Estates, microbiologists and Infection Prevention and Control teams must be engaged from the early stages of design of any refurbishment project, to ensure optimisation of ventilation systems in line with the proposed clinical use.

Work force

> *(A weaning unit should have) "staff who were interested in the "failures" – that can't breathe on their own."*
>
> *"The right kind of professional having a presence on the ward, getting to know them over time means*

Medical

Medical consultants working on SWUs will typically have a certificate of completion of training (or equivalent) in intensive care medicine, respiratory medicine or both. They should all have experience and competence in managing patients receiving acute and long-term ventilatory support. Their current workload should include a service commitment to the co-located Complex Home Ventilation service. SWUs may also include staffing by a non-medical consultant workforce. Numbers of consultants should be sufficient for local requirements but there should be at least four consultants with a substantial commitment to the SWU.

Medical consultants will have timetabled sessions on the SWU without other clinical commitments preventing them attending the unit urgently. A consultant rota for referrals to the SWU should be in place.

Each patient on a SWU should be reviewed at least once a day by a consultant according to locally agreed policy. Admissions to a SWU should take place between 08:00 and 18:00 unless otherwise agreed by the accepting consultant. New admissions must be reviewed by a consultant on admission.

Postgraduate doctors in training from respiratory and critical care programmes will benefit from rotation through a SWU and will gain valuable experience and competencies during their time on the unit. A separate rota should be considered depending upon the size of the SWU. A senior decision maker (ST3 equivalent and above) with the required competencies should be available to assess patients within 30 minutes of admission or deterioration and in accordance with NEWS2 protocols (16).

Advanced Care Practitioners (ACPs) have been a valuable part of the critical care workforce for the last decade, as have physician/anaesthesia associates (PAs/AAs) in medicine and anaesthesia. Depending upon medical staffing availability and rotas, ACPs or PAs may have a similar role on SWUs in staffing a non-consultant rota.

Nursing

> *"I did not know who I was. What time of day it was? Who was supposed to be looking after me?"*
>
> *"I saw a different nurse each day. Some were nice, some were indifferent. Some talked to me either as a child or as an adult and some talked at me. Some did not talk to me at all."*
>
> *(Patients on an SWU would benefit from being) "given choices"*

Registered nurses working in a SWU have a central role within the multi-professional team shifting the care focus and planning from acute care to holistic rehabilitation, recovery and preparation for discharge (appendix 5).

We recommend nurse-to-patient ratios adhere to recommended published guidance, with a minimum ratio of 1:2 for ventilated patients (17,18). Staffing for non-ventilated patients should be dependent upon patient acuity, multi-professional team staffing, and the physical layout of the unit. Nurse staffing must include a supernumerary 24/7 nurse shift coordinator with responsibility for the clinical supervision of patients and staff.

The senior nursing team should comprise: a nurse manager and a nurse educator. These posts would be supernumerary. The nurse manager would be responsible for maintenance of the service, quality improvement initiatives, liaison with other services including outreach (both inward and outward) and strategic development (including research) alongside the medical director. The nurse educator would be responsible for ensuring SWU nurses achieve and maintain competency in management of patients experiencing prolonged weaning and associated equipment.

Larger units should be encouraged to develop the nurse consultant role to complement the role of the nurse manager and senior medical team and ensure effective communication between acute and community services.

Physiotherapy

> *(Patients on an SWU would benefit from being) "part of planning their own care."*

Physiotherapy is an integral part of the multi-professional team approach to weaning patients with complex ventilation, who often have multifaceted needs around rehabilitation. Interventions delivered by respiratory physiotherapists include secretion management, cough augmentation, advanced ventilation strategies, mobilisation, and rehabilitation. This is not an exhaustive list and should be expanded dependent on the services required and clinician skills, for example arterial and capillary blood gases. Together with therapy support workers and the wider team, physiotherapists have a key role in early mobilisation and weaning initiation to mitigate the risks of prolonged mechanical ventilation, including improving functional independence, minimising inpatient length of stay and facilitation of a timely and effective discharge from the SWU.

An experienced respiratory physiotherapist with highly specialist knowledge (19) should be appointed and work with the lead medical consultant and lead nurse. This

individual will have advanced clinical knowledge and experience in the management of patients with complex ventilation and weaning needs, rehabilitation, leadership and management. They will share responsibility for training and development of the SWU team. A job plan for such a post will include all key areas of advanced practice and have dedicated time for clinical work alongside leadership, research and service/quality improvement. Maintaining a good skill mix is vital and will include support from senior permanent and rotational physiotherapists (19). Larger units may develop the role of a consultant physiotherapist.

Each patient's acuity and rehabilitation needs should be considered and is dependent on their clinical complexity. This will require working in conjunction with the wider AHP team and may require protected time and access to a suitable rehabilitation facility to provide rehabilitation.

24 hour, 7-day cover should be provided utilising on-call physiotherapists who will have adequate training to ensure they can manage complex ventilation patients. At least 0.25 Whole Time Equivalent (WTE) physiotherapist per weaning bed is recommended which should be in addition to the physiotherapy complement within the complex long term ventilation team (17).

Dietetics

> *"I always felt really hungry and thirsty."*

Patients in a SWU are at a high risk of malnutrition or excessive weight gain, both of which are harmful to respiratory weaning and function. Patients are likely to need short and long term enteral or oral nutritional support. Furthermore, patients might be at risk of nutritional deficiencies given the low energy needs of some underlying causes of neuromuscular disease states.

A dietitian with expert knowledge on long-term and individualised nutritional support, management of complex and chronic nutritional tolerance issues, feeding tubes, pre-gastrostomy counselling and rehabilitation is essential and should be identified as a service lead. A background in critical care dietetics is valuable. A SWU must have access to a dietitian five days a week during working hours. A staffing level of 0.05-0.1 WTE per SWU bed is suggested (17). Specific competencies should be created to ensure staff have the appropriate training and skills. Dietitians should consider extended scope practitioner roles such as gastrostomy balloon changes, using indirect calorimetry to determine energy expenditure and supplementary prescribing where applicable.

Occupational Therapy

> *"A routine / plan for each day – achievable goals so we don't keep failing."*

Occupational Therapists (OTs) are integral to rehabilitation and complex discharge. SWU OTs should have experience in complex discharge planning, respiratory, critical care and neurological conditions.

OTs work with patients, both on a one-to-one basis and in a group setting, to facilitate progress towards performance-based goals with the aim of the patient returning to activities that they need and want to do. Participation in meaningful activities can aid restoration of a person's identity, sense of purpose, restore wellbeing, and enable quality of life during the process of ventilation weaning.

OTs are dual trained in physical and mental health and carry out holistic assessments and interventions which consider a person's physical and cognitive function and psychosocial needs. OTs also consider a person's physical environment and can prescribe equipment, aids and adaptations to optimise the home environment for a safe discharge.

OT staffing ratios will depend on the SWU size but the ideal ratio is defined in the general rehabilitation guideline (20), with 0.2 WTE OT per weaning bed able to offer 45 minutes of rehabilitation per day.

Due to the complex nature of this patient group, it is recognised this clinical area requires a more experienced and senior workforce to supervise the team. Best practice is a full 7-day service as weekend working could add therapeutic benefits. Availability in job plans for community visits to patients' homes can increase effective and safe discharge.

Psychology

> *"I had no control."*
>
> *"Psychological support we feel is really important as there can be many changes and traumatic events taking place that deeply affect patients and families which you somehow have to cope with and carry on."*

Practitioner Psychologists (HCPC registered) with expertise in long-term ventilation and enhanced communication skills can address psychological barriers to weaning and optimise the patient journey. SWU patients should undergo psychological assessment/formulation, identifying needs and informing the weaning plan.

When indicated, patients should receive psychological intervention. The psychologist works directly with patients (and families) and jointly/indirectly with the SWU team, to ameliorate psychological (anxiety, trauma, depression, panic), cognitive (memory, concentration, delirium) and physical (fatigue, pain, sleep disruption, breathlessness) symptoms.

Greatest impact is achieved through integration of the psychologist within the SWU. This promotes a culture of psychological understanding via training and consultation,

and through reflective practice and staff support regarding psychologically complex/emotive cases. In recognising the existing expertise in biopsychosocial support within the weaning workforce, the psychologist supports structured dissemination of psychological skills/techniques and achieves the widest reach of psychological support.

The psychologist should participate in clinical team/ward-rounds, service development and research/audit activity. Workforce planning should sufficiently include the above roles (in-line with size of unit). Breadth and integration of the role requires a senior psychologist (minimum 0.5 WTE) professionally embedded within clinical health psychology services for weaning and long term ventilation.

Pharmacy

Critical care pharmacists have been shown to improve safe use of medicines, decrease length of stay, reduce mortality and improve economic outcomes (21,22). Clinical pharmacy services contribute to compliance with the NICE Quality Standard (23) for completion of medicines reconciliation within 24 hrs of admission, and on discharge from secondary care. Pharmacy services can support compliance with CQC mandated safe and secure handling of medicines standards (24).

The role of the pharmacist includes individual patient review and participation in SWU ward rounds. They also provide support in clinical guideline development, medicines optimisation activities, medication incident reviews and medicine use evaluation/audit and expenditure analysis. National recommendations for Enhanced Care areas, endorsed by Faculty of Intensive Care Medicine, UK Clinical Pharmacy Association and Intensive Care Society, have been published and provide guidance relevant to a SWU (25). They describe the direct patient-facing pharmacy services required, as well as the indirect/non-patient facing pharmacy services required for the safe and timely provision of medicines to clinical areas (22,23).

Pharmacy provision will be dependent on the number of beds within the SWU but access to clinical pharmacy services is required 7 days a week. The pharmacy service provided outside standard working hours will vary depending on the size, complexity and admission/discharge activity of each SWU. The SWU pharmacist should be competent in the medication management of patients on non-invasive respiratory support and complex respiratory conditions, with appropriate advanced stage I skills (UKCPA) and access to advanced level critical care pharmacist advice/referral.

Medicines Management Technicians work closely alongside pharmacists and provide medicines support services to the SWU team, including medicines reconciliation, patient counselling, provision of medicines, and education and training of staff. Pharmacy assistants can support SWU colleagues by provision of medication to the clinical area/bedside, expiry date/fridge checks, provision of medicines, management of emergency trollies and kits, transfer bags and top-up services. These additional roles should be considered when planning pharmacy services for SWUs, as they can potentially release nursing/health care assistant time spent on medicines related activities.

Speech and language therapy

> (The thing that kept me going was) "being able to talk again with my cuff down."
>
> "Support with communication, ability to watch tv, use an iPad or computer are things that are set up at home specific to the persons needs but on coming into hospital are lost even if there is general provision on the ward."

Speech and Language Therapy intervention is essential for optimising communication, swallowing, weaning and decannulation outcomes, such as time to oral intake and early voice restoration (26,27). All patients with a tracheostomy, and those with communication, voice, swallowing and secretion management needs should be assessed by a lead speech language therapist (SLT) with appropriate expertise, skills and training. SLTs should also be competent to contribute to weaning, augmentative communication and alternative feeding decisions.

SLTs should have expertise in the rehabilitation and management of patients with tracheostomy and ventilation dependency and potential impact on swallowing and communication and have advanced knowledge of Continuous Positive Airway Pressure (CPAP), NIV and High-Flow Nasal Oxygen (HFNO) therapy. To manage dysphagia effectively and efficiently, SLTs will need to be competent to perform instrumental swallowing assessments including Flexible Endoscopic Evaluation of Swallowing (FEES) and video-fluoroscopy, as per the Royal College of Speech and Language Therapists position papers (28). In collaboration with the SWU MDT, SLTs should also be capable of using video nasendoscopy to identify dynamic laryngeal obstruction due to upper airway dysfunction to optimise the use of NIV and Mechanical Insufflation-Exsufflation (MI-E). Expert skills in communication assessment and support to facilitate mental capacity decisions are essential.

The SLT staffing requirement for SWUs will be dependent on the number of SWU beds, complexity, acuity and needs of patients. A minimum staffing level of 0.1 WTE SLT per SWU bed is suggested (17). The SLT service should be provisioned for a minimum of five days a week access. Sufficient capacity should exist for direct clinical care encompassing assessment and therapy intervention and there must be additional capacity enabling protected time to support the SWU's wider functions. These will include SWU team meetings and follow-up clinics, engaging in audit, service evaluation and quality improvement, and developing and contributing to research, education and training.

Palliative care

> "The weaning unit should have access to specialist skills and expertise specific to the end of life care needs of younger patients and those with additional developmental needs."

There must be locally agreed protocols detailing the general principles of withdrawal of respiratory support and oxygen therapy whilst recognising that withdrawal in individual patients will be a bespoke process.

In appropriate patients, there should be a post-discharge pathway to ensure that patients can access community palliative care and hospice care.

There should be availability of a palliative care team seven days a week and access to out of hours advice.

Patient Pathways

Specialist advice

SWUs should offer access to advice and support to ICUs to facilitate the care of patients undergoing difficult weaning. SWUs may offer specialist advice more widely to support more complex cases, when local services are not available, or if they involve patients already known to the SWU. Most patients requiring advice from SWUs will have failed conventional attempts to wean from IMV, an established tracheostomy at the time of referral and already completed at least 21 days of IMV. Discussion earlier in the patient pathway, including prior to initiating IMV, may be relevant for patients with pre-existing conditions that are expected to be associated with weaning failure; these include patients with neuromuscular disease, severe respiratory disease or those already established on home ventilation.

When difficulty in weaning is anticipated, it is important to access advice for these patients early in the process, as the chance of successful weaning reduces with each additional day of IMV. Advice should be accessible via telephone and email with a response time for non-urgent calls of 24 hours. Contact details should be readily available on the service website and an on-call rota for provision of advice provided to the hospital switchboard to facilitate access as needed. Each SWU should have a system for recording referrals and advice provided to audit referral data and decision making. The contact point for advice should be a consultant grade clinician capable of assessing patients with complex weaning failure and have experience in weaning and home ventilation.

Referral criteria

Individuals who will benefit from transfer to a SWU are listed in the Patient Cohort section above. Examples of referral pathways are included (appendices 6, 7, 8). The local critical care networks will facilitate this process.

The SWU will prioritise patient transfers based on the chance of successful weaning and thus the potential to add value to patient outcomes. Patients with established neuromuscular disease are more likely to benefit from early intervention than patients with weaning failure due to severe post-critical care or post-surgical

acquired weakness. These patients are less likely to require transfer but may benefit from specialist advice regarding weaning plans including early deflation of tracheostomy cuffs and rehabilitation strategies.

Assessment

SWUs should offer a range of pathways for assessment of patients who are experiencing weaning failure. The mode of assessment should meet the needs of the patient and should include remote advice on weaning strategies and rehabilitation and, on-site assessment at local ICUs. Adequate time in job plans must be available for remote assessment. Transfer to the SWU for a period of assessment may also be appropriate. The length of a SWU admission for assessment should be defined prior to acceptance and transfer.

The assessment of patients with complex weaning failure requires a comprehensive review from the SWU multi-professional team. The opinion from all members of the team will be utilised to conclude on weaning potential and acceptance to the SWU.

Patients may be accepted for transfer or for provision of remote advice to support weaning at the local ICU. This advice may involve various members of the multi-professional team as required to support professionals in the referring ICU, for example by providing advice on optimisation of MI-E for airway clearance. Remote support should be a dynamic process with ongoing advice and re-assessment in collaboration.

Patients accepted for transfer are unlikely to be admitted immediately to the SWU due to bed availability and it is important that weaning does not stall in this period. Bespoke weaning plans should be provided during this period to progress weaning pending transfer, with weekly updates between the referring ICU and the SWU.

Treatment and monitoring

Monitoring

Following admission to a SWU, observational monitoring will be non-invasive. Cardiac monitoring including non-invasive blood pressure, respiratory rate and saturation levels should be available and centrally displayed until the patient is deemed medically stable. Once medically stable, 24-hour cardiac monitoring can be discontinued and replaced by regular non-invasive observation of vital parameters. The frequency of these observations will be determined by local protocols.

Additionally, non-invasive transcutaneous CO_2 monitoring is an essential monitoring parameter during weaning and/or optimisation of ventilation.

Existing national guidance should be followed regarding end tidal CO_2 ($EtCO_2$) monitoring requirements (29). However, it must be noted that when using leak ventilation circuits on domiciliary ventilators, $EtCO_2$ is inaccurate. Other intermittent

monitoring strategies should be employed such as transcutaneous CO_2 monitoring or arterial/capillary blood gas sampling according to local protocols.

All ventilators used with the SWU should have audible alarms and ideally units should have a central system to display ventilator alarms.

Core essential clinical monitoring must include

- At least daily SWU team ward rounds
- Senior medical and nursing clinician available 24/7 to help with decision making and patient assessments.
- Weekly multi-professional team review and discharge planning meeting

Treatment and Management

The overall treatment and management for patients admitted to a SWU uses a patient centred whole-body rehabilitation framework (appendix 9) delivered through a collaborative multi-professional team approach. This should include:

- Individualised weaning and rehabilitation goals and plan developed in consultation with the patient and family as able
- Established local weaning protocols, including use of NIV, from which to draw the individualised weaning goals
- Optimisation of rehabilitation and long-term ventilation leading to an agreed collaborative discharge pathway for tracheostomy ventilation or NIV
- Standard core care strategies within the whole-body rehabilitation framework (appendix 9)
- Intravenous drug therapy but no use of inotropes or vasopressors that require invasive monitoring
- Access to sleep studies to diagnose and optimise ventilation management
- Ceilings of treatment discussed for and with each individual patient and their family on admission and during ongoing treatment with access to palliative care specialist teams when appropriate.

Equipment

> *"We think that strong links with an assistive technology team could make a big and positive difference to patients with a disability."*

SWUs need large amounts of equipment with adequate storage space. Exact requirements will depend upon the size and location of the SWU, but typical requirements are listed in appendix 10.

Local policies should be in place to define the frequency of changes of respiratory equipment for infection control purposes.

Discharge and commencement of NIV/TV

> *"We think it would be great to have a hospital to home link nurse/professional to help with the transition from hospital to home, which can feel scary and daunting when the patient is going home in a very different situation to when they were admitted."*
>
> *"Support with changing tracheostomy tubes at home, help with training for carers, assistance with medical issues as they arise and liaison with the hospital staff would feel very supportive."*

A SWU should be co-located with a complex long term ventilation service to facilitate discharge. A complex long term ventilation service must have extensive and ongoing experience in the management of home tracheostomy ventilation, ventilator dependent patients and ventilation of patients with progressive neuromuscular disease, including genetic muscle disease and motor neurone disease.

Discharge complexity will depend on the patient outcome. Patients may be weaned completely, on nocturnal NIV, or fail to wean and remain permanently tracheostomy ventilated. Care packages may be required and are likely to be more extensive and take longer to organise in the case of discharge with tracheostomy ventilation. Location of care may be home or an intermediate care facility (prior to home or as the intended permanent destination). SWUs may need to repatriate patients who cannot be weaned back to the referring hospital and commissioning pathways should be in place to facilitate this along with local formal agreement to prioritise repatriation transfers within 48 hours (17). In such cases SWUs will continue to be available for ongoing advice and support. When patients are repatriated a comprehensive multi-professional team handover is provided detailing assessment, reasons for weaning failure and plan for the patient's ongoing respiratory care and rehabilitation.

Most patients weaned from IMV will have made significant physical and cognitive improvements but may still require further support if they have not reached their previous level of independence. Discharge planning for weaned patients requires a comprehensive functional assessment by all SWU team members to establish further rehabilitation and care needs post-discharge and to optimise the home environment.

Discharge planning should commence on transfer to a SWU. Every SWU must have a checklist for discharge displayed so the patient, family and all SWU team members can understand progress to discharge and who is responsible for the next step in the pathway. There should be an identifiable individual or team leading the discharge who may or may not be part of the SWU team according to local policy. Education of the SWU and critical care teams will facilitate understanding of the discharge process. Lead SWU clinicians should work with local commissioning groups to streamline this process as much as possible and reduce geographical variation. This will include developing, commissioning and maintaining training within intermediate care facilities.

The patient, family and SWU team need to agree on a discharge destination considering patient/family wishes, family carer burden and the safety of management of tracheostomy ventilation in the community and the home environment. Patients should have a clear list of whom to contact for consumables and clinical issues once discharged. (Appendix 11).

After discharge, there must be a clear re-admission pathway agreed between the local hospital and the SWU. Patients and families should have access to a 24/7 helpline for clinical and equipment enquiries. Making an Emergency Health Care Plan (EHCP) should be strongly encouraged. SWU clinicians must have time in their job plans to do this.

In line with NICE guidance, medication reconciliation with clear documentation of changes (including rationale) must occur at admission, discharge and throughout the patient's stay (23). Patients often have complex medication needs, are under multi-speciality care, with frequent transitions between care providers. These factors increase the risk of medication error. In addition, these patients often have complex care needs, rely on carers or family members to manage and administer medicines, and may struggle to access primary care services. A clear plan should be documented for each medicine on discharge with information, equipment and counselling provided for the patient, family, care agencies/providers, GPs and community pharmacies.

If discharge is to home or an intermediate care facility, the patient's GP must be contacted and receive a detailed handover of the events during hospital admission and what complications may be anticipated following discharge.

Follow up

Following discharge, patients often experience the same problems as those experienced by patients following discharge from critical care. Follow up should involve the SWU multi-professional team where patients are discussed and a follow up clinic appointment arranged based on individual patient need. SWU follow up clinics must have access to the SWU multi-professional team and the ability to refer to specialist clinics such as decannulation or airway clinics.

After initial follow up with the co-located complex home ventilation service, patients must have ongoing follow up depending upon their needs. As a minimum, this should be with a complex home ventilation team if patients are tracheostomy ventilated or ventilator dependent, a non-complex home ventilation team if weaned to nocturnal NIV, or a respiratory team if weaned completely. If care continues in local hospitals, handover between teams is essential. There must be time in the SWU team member job plans to enable follow up.

Follow up for patients with a tracheostomy is essential with plans for review of weaning and decannulation, clear protocols for changing the tracheostomy tube, review of weaning and emergency management in the community.

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Appendices list (Appendices separate to main document)

1. Patient Story 1
2. Patient Story 2
3. QI Tool
4. NIV/CPAP Safety checklist
5. Whole body rehabilitation care strategy
6. Pathway flowcharts
7. Referral criteria
8. Referral flow diagram
9. Whole body rehabilitation pathway
10. Equipment list
11. Product/consumables list