INFORMATION ABOUT THE AFTER CARE OF PATIENTS TREATED WITH ECMO.

BACKGROUND:
Extracorporeal membrane oxygenation (ECMO) is an advanced life support therapy used for patients with severe cardio-respiratory failure refractory to conventional techniques. Guy’s and St Thomas’ Foundation Trust (GSTFT) is one of the 5 nationally commissioned ECMO centres that provides centralised care for patients requiring this highly-specialised treatment. Although GSTFT, primarily, covers South East England, we work closely with other centres to manage patients throughout the whole of the UK. ECMO is similar in concept to cardiac bypass, used for heart surgery, only it is used for a prolonged period (days to months) for patients with potentially reversible cardio-respiratory failure. To commence ECMO, the patient requires one, two, or more, large venous or arterial cannulae (23-31 French Gauge) placed percutaneously in the femoral and/or jugular vessels. At GSTFT, we continue managing the patients until they have recovered from their critical illness or are at a low level of dependency and not requiring further ventilatory support.

In common with other patients who have been admitted to ICU, there are a problems that will need to be addressed in the period following repatriation to the referring hospital and after hospital discharge.

POST INTENSIVE CARE SYNDROME (PICS): is the combination of health problems that remain after critical illness. They are present when the patient is in the ICU and may persist after the patient returns home. These problems affect three broad functional domains:

1) physical
2) psychological
3) cognitive

PHYSICAL:

ICU-ACQUIRED WEAKNESS:
Long periods of ICU are accompanied by pronounced neuromuscular deconditioning and this process can be exacerbated by high dose steroids that may have been used to treat acquired inflammatory lung conditions. Patients will need an early evaluation from a community-based physiotherapist to determine whether a musculoskeletal and/or pulmonary rehabilitation programme is required.

LUNG FUNCTION:
- Many patients have a return to near normal lung function by 12 to 24 months following their episode of severe respiratory failure.
- Glucocorticosteroids are used in high doses in patients with severe respiratory failure that develop acquired interstitial lung disease (ILD). These patients require specialist respiratory input and will be given an appointment in the ILD clinic at GSTFT with Dr Boris Lams and Dr Nina Agawal or referred to local specialist respiratory physicians.
- Laryngeal dysfunction is common following ventilation for a prolonged period. Ongoing hoarseness or changes in their voice may indicate vocal cord damage. So please refer to your local voice clinic OR Miss Chevreton at GSTFT. Breathlessness and/or stridor may suggest tracheal strictures that will also require referral to an ENT surgeon.
- All patients that have suffered severe respiratory failure requiring ECMO support require annual vaccination for influenza and they should have a Pneumococcal vaccination.
CANNULA SITE ASSESSMENT:
It is important to assess the cannula sites in these patients to identify any early and late complications.
- Suture should be removed at 10 days following decannulation
  - ECMO cannulae removal involves placing two sutures in the skin at the cannula entry point. The ECMO discharge summary includes the date of decannulation.
- Infected cannula site wound is possible.
- Deep vein thrombosis
  - All patients undergo an ultrasound doppler following decannulation to assess whether a deep vein thrombosis has developed secondary to the vein cannulation. Some patients will leave hospital anticoagulated with warfarin or novel anticoagulant agent for 3-months treatment.
  - All will be given an appointment in the Thrombosis clinic at GSFTF or with their thrombosis service locally.
- Pseudo-aneurysms or strictures
  - If the artery has been cannulated, aneurysms or strictures can occur. This manifests as pain due to compression of the femoral nerve and lower limb swelling from venous outflow obstruction due to venous compression or deep vein thrombosis formation. An ultrasound doppler to confirm the diagnosis and then referral to a vascular surgical opinion is required. We are always happy to be contacted to advise on the most appropriate action if a complication develops.
- The cannula sites may also leave a scar that may require elective plastic surgical revision in the future should the patient wish.

PSYCHOLOGICAL SEQUELAE:
- Many ICU patients suffer significant delirium during their ICU stay and these memories persist once home. In the ICU, delirium is often managed with the use of benzodiazepines and/or antipsychotic agents (e.g. quetiapine). These are usually discontinued prior to discharge home and if they are not then they need to be weaned and ceased.
- Anxiety, depression and post-traumatic stress disorder with flashbacks of disturbing hallucinations and memories are common following admission to the ICU. Patients need assessment and psychological support to be offered e.g. an iAPT referral if they are suffering with recurring frightening memories from their time in the ICU.

COGNITIVE IMPAIRMENT:
- Between 30% to 80% of patients may have cognitive impairment after leaving the ICU. Some improve during the first year after discharge from the hospital; other people may never fully recover. A hypoxic insult is often implicated for the younger patients and some may have suffered with cerebral bleeding while on ECMO.
- Referral to the Post Critical Care clinic or a local memory clinic is advised.

POST CRITICAL CARE CLINIC:
- All patients will be given an appointment in the Post Critical Care clinic at GSTFT for 2-3 months following discharge from hospital. If this has not occurred please email: ICUclinic@gstt.nhs.uk
- This is a multi-disciplinary clinic that undertakes a thorough functional assessment to assess to what extent the patient is suffering with Post Intensive care syndrome.
- The multidisciplinary team consists of critical care; consultant physicians, nurses, physiotherapist, occupational therapist, a neuropsychiatrist and a clinical psychologist.
- Each new patient spends 3 hours in the clinic seeing each member of the MDT and visits the ICU where they were treated with ECMO support.
If you think your patient could benefit from attending the Post Critical Care clinic and has not received an appointment please email: ICUclinic@gstt.nhs.uk
PEER SUPPORT:
Patients and relatives often need to talk about their experience of surviving critical illness and peer support groups offer the opportunity to talk with other patients and relatives. GSFTF have a peer support group so please encourage patients to attend and ask them to contact: ICUpeersupport@gstt.nhs.uk or if living outside London then refer patients to ICU steps, the intensive care patient support group website: icusteps.org/support.

We are always happy to be contacted about any patient who has been managed by the GSTFT ECMO Service. Please contact 02071883368 and ask for ECMO consultant or nurse in charge.

SUMMARY of GP REVIEW/ACTION POINTS:

1. ECMO survivors are at high risk of Post Intensive Care syndrome – please refer patients who have not received an appointment to the Post Critical Care clinic at GSTFT email: ICUclinic@gstt.nhs.uk
2. Vaccinate: Flu annually and Pneumococcal polysaccharide vaccine
3. Review ECMO cannulae sites for complications e.g. retained sutures, wound infection and keloid scar formation
4. Medicine reconciliation – specifically steroids, anti-psychotics and anticoagulation. There should be a clear plans for these medications in the hospital discharge summary. Please contact the ECMO team on 02071883368 and ask for the ECMO consultant or nurse in charge to clarify plans if not clear.
5. Ask patients about frightening memories of ICU and if they are recurring or if they are experiencing new symptoms of anxiety and/or depression. Refer to the Post Critical Care clinic by emailing ICUclinic@gstt.nhs.uk and/or make an iAPT referral: Find Psychological therapies (IAPT) services - NHS Choices.
6. Sign-post patients and relatives to Peer support groups run at GSTFT: ICUpeersupport@gstt.nhs.uk or by ICU Steps icusteps.org/support and to the Facebook group: ECMO adult survivors.
7. Contact GSTFT ECMO team with any queries or concern (02071883368).