Guidelines for Withdrawing Non-Invasive Ventilation (NIV) in Patients with MND

1 Withdrawing NIV in Patients with MND

Some patients will wish to discontinue their NIV as a matter of choice. It is important that when discussing and/or initiating NIV a discussion takes place about how much treatment they would want and when they might decide they no longer want it. It would be better to initiate the discussion at an earlier stage rather than in the last few days of life – although this may change when the disease progresses. They should be told that it is likely to lead to their death, potentially in a matter of minutes but sometimes extending to a few hours or even days. A competent patient is entitled to make such a decision. It may cause considerable concern for some members of the patient's family or healthcare professionals and managers, as the patient's choice may be viewed by some as tantamount to assisted suicide. However, what is taking place is the patient (or their proxy) taking an active decision to refuse a medical treatment or have it withdrawn, which from a medical ethics perspective is not assisted suicide.

Complex emotional issues may arise around the withdrawal of NIV for families, carers and health professionals. These need to be addressed before the withdrawal of NIV, and the need for bereavement care should be addressed at an early opportunity. Staff support mechanisms, including the possibility of a staff de-briefing meeting, need to be considered.

The patient may choose to withdraw NIV at home or in an in-patient setting such as at the Hospice or Glenfield Hospital.

2 Background Information about Ventilation

Patients with MND are usually on NIV using Pressure Control mode. This mode means their breathing pattern is controlled by the ventilator and facilitates resting of the respiratory muscles. However, some patients may find this level of "controlled breathing" difficult to acclimatise to and so may be on Pressure Support. This is a mode which is much more readily controlled by the patient's own inspiratory and expiratory effort and so patients may be able to synchronise with the ventilator more easily. Generally there is little benefit in switching between the modes, certainly not during a period of withdrawal of treatment, but the aim is to always try and utilise settings and modes which best suit the patient and maximise comfort and compliance.

Generally, the preferred method for discontinuing ventilation would be to provide adequate sedation for the patient and then just remove/discontinue the NIV and oxygen (if used). The key then would be to ensure maximum palliation of dyspnoea and other symptoms. It is not common practice to "wean" patients by altering settings as this can prolong the situation and the potential discomfort experienced by the patient.

3 The Process of Withdrawing NIV

When a patient using NIV requests its withdrawal, the reasons for the request should be explored and the other options available considered.

If a patient is not 24 hour dependent, they may choose not to continue with NIV at any point by simply not replacing their mask. This may lead to increased dyspnoea requiring appropriate symptom control.

If a patient is 24 hour dependent on NIV and wishes to discontinue its use, the principles are the same but death is likely to follow more closely. Forward planning is required to ensure that the patient does not experience distress at the time of withdrawal.

4 Involvement of the MDT

Discuss with and inform the wider team of the patient's decision (MND CNSs, GP, district nurse, Hospice @ Home, SLT, dietician, OTs, physios, complementary therapists).

Ascertain team members' views and give anyone who does not wish to be involved the option of withdrawing from that patient's care.

Which professionals need to be present will vary from case to case. This should be planned ahead to ensure availability. There will need to be a nurse and doctor available, possibly for up to 48 hours.

5 Anticipatory Prescribing

As there is such a variation between patients of current medication, each case must be discussed as a team, including the Palliative Medicine Consultant/Specialist Registrar and other doctors and nursing teams involved.

Drugs may include opioids, benzodiazepines, phenothiazines or other sedatives.

Using the intravenous route may facilitate titration and a syringe driver may be required.

6 Practicalities

6.1 Discussion with patient, family/carers and involved professionals is required to ascertain that they all understand that:

(i) A competent patient has the right to stop any treatment they are receiving.

(ii) Stopping NIV if dependent on it 24 hours a day, is likely to result in death shortly afterwards – from a matter of minutes, or sometimes extending to a few hours or even days.

(iii) Complying with the patient's wishes is good medical practice (and in line with the law) and not Physician Assisted Suicide or Euthanasia.

(iv) Formal Advance Decision documentation should be completed and reviewed frequently to ensure all carers are aware of the patient's wishes and choices.

6.2 **Consider the practicalities** with the patient, family/carers and involved professionals covering:

(i) Where will the process occur – home, hospice or hospital?

(ii) The medication required to ensure comfort.

(iii) Potentially starting a syringe driver 12 hours before the mask is removed if there are uncontrolled symptoms of anxiety or breathlessness.

(iv) The probability that bolus injections will be required to maintain comfort, including IV sedation.

(v) Who will remove the NIV mask?

(vi) Who will switch off the ventilator?

(vii) Identify a keyworker to co-ordinate the process.

6.3 **Discuss with the patient and family**:

(i) Who wants to be there at the time of death?

(ii) Who will remove the mask – professional or family member?

(iii) The possibility of gasping, changing colour, etc.

(iv) The uncertainty in how long it may take to die after stopping NIV.

6.4 **Differences for patients at home** compared to hospice inpatients need to be considered, such as the availability of professionals who may need to be present for several hours in a patient's home, and the provision of privacy at home when professionals are also present. The GP is likely to be much more involved with a death at home.

6.5 **Time scale**

(i) When does the patient want to stop NIV?

(ii) How much warning is required?

(iii) Who needs to be available?

(iv) Drugs - ensure that sufficient medication is available. A patient who has been on morphine and/or benzodiazepines for some time is likely to require an increased dose due to drug tolerance.

6.6 **The actual withdrawal of NIV**

(i) Site IV access or use s/c route.

(ii) Titrate medication as needed to achieve satisfactory symptom control (so they are not distressed when the ventilation is stopped).

(iii) Switch off the ventilator when symptoms stable and remove the mask.

(iv) Observe closely while remaining unobtrusive.

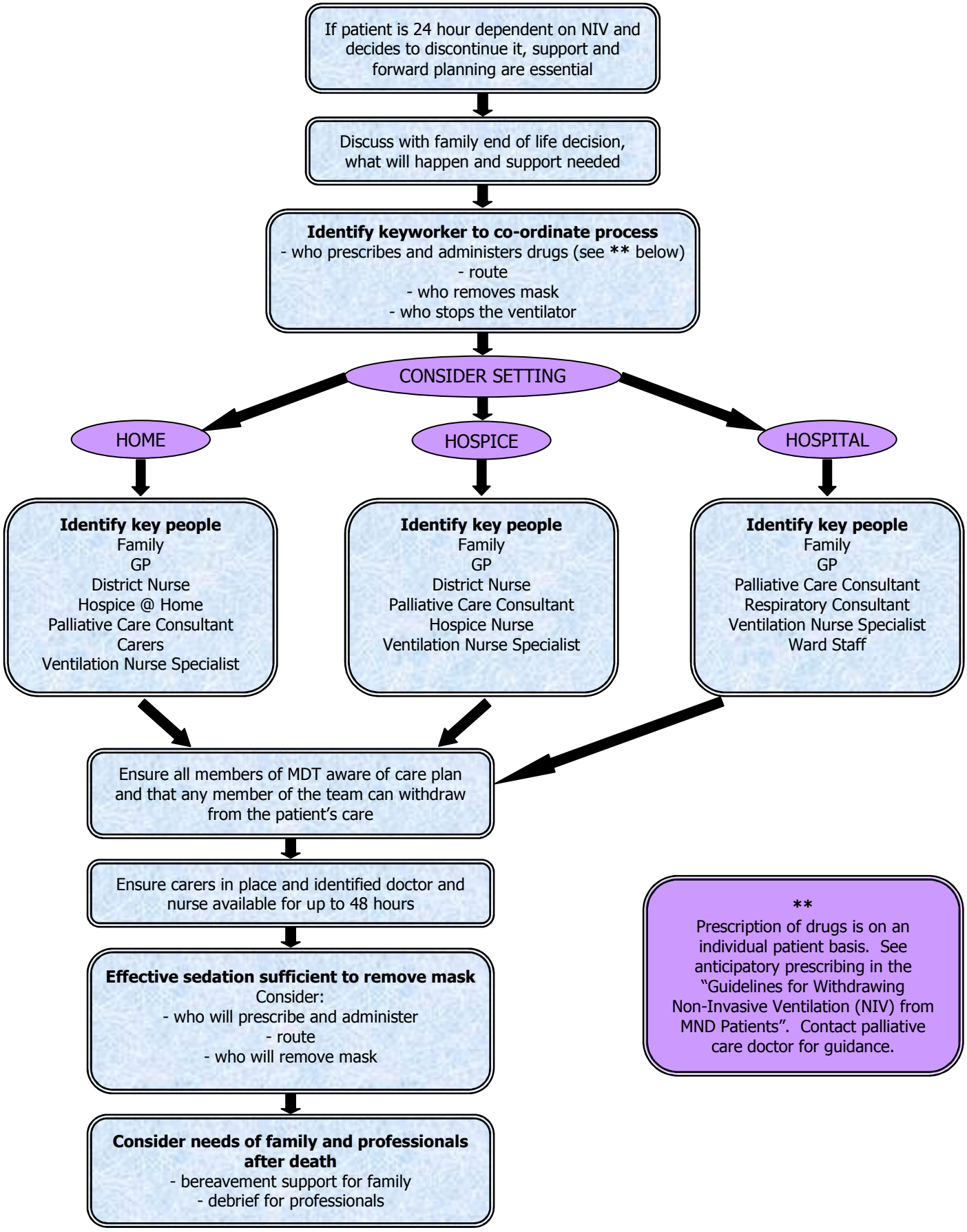
(v) Ensure the patient remains symptom controlled until death occurs. This may take from minutes to several hours.

6.7 **After death**

Bereavement support should be available to the family and carers acknowledging the complex emotional impact of withdrawing NIV. Debriefing and support should be available to the professionals involved.

Preparation For Stopping Non-Invasive Ventilation (NIV)

This is to be read in conjunction with the "Guidelines for Withdrawing Non-Invasive Ventilation (NIV) from MND Patients".



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