IMPRESS

Improving and Integrating Respiratory Services

IMPRESS response to Department of Health (England) End of Life Care Strategy: Quality Markers Consultation

IMPRESS response to Department of Health (England) End of Life Care Strategy: Quality Markers Consultation (http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_090077)

Overarching comments

1. IMPRESS (www.impressresp.com) is a joint initiative between the General Practice Airways Group (GPIAG) and the British Thoracic Society (BTS) to improve and integrate respiratory services in the NHS. This response therefore represents the combined views of clinicians from primary and secondary care, a number of whom are also commissioners. It looks at the document from a respiratory perspective, taking account of the relevant respiratory diseases: lung cancer and chronic obstructive pulmonary disease (COPD) as well as the end-stage of those with respiratory failure due to interstitial lung disease and motor neurone disease.

2. We welcome the end of life strategy and the creation of quality markers and this consultation. However it is an evolving field and therefore it is important that will be opportunities for improvement and refinement as the evidence emerges.

3. We would expect that the markers would align with the national Clinical Strategy for chronic obstructive pulmonary disease (COPD) that is due for publication shortly. This is important because it contains a chapter on advanced disease and end of life, which represent complex challenges to those providing support for people with COPD.

4. We also strongly recommend that any conclusions reached on quality markers are reflected in the General Medical Services Quality and Outcomes Framework (QOF) to ensure consistency.

5. We would also expect that as implementation of the End of Life Care Strategy features in the Operating Framework for 2009/2010 it will be given a high priority in local planning by PCTs. We also note that there is one end of life care Vital Sign: “Proportion of all deaths that occur at home.” We fully agree that there are people, particularly those in care homes, who would have a much more dignified end of life if not admitted to hospital. However, there are some problems with this. Firstly, for patients who are breathless from COPD, and very often isolated, hospital is often their, and their carers’ preference. This should be recognised in local end of life strategies and taken into account when looking at the data. It is the quality of the experience rather than the location that is important. Perhaps a more useful measure would be proportion of deaths (in the given population) that are planned and that occur in the planned place?

6. We also agree with the findings of the National Audit Office report and the supplementary RAND Corporation report that there are opportunities to use the NHS’s combined resources more equitably, efficiently and effectively. However, we do not think that a single *optional* level 3 Vital Sign is sufficient to drive up standards given the current deficits in end of life care and the inequalities between different patients and different PCTs that exist. We understand that there is no scope to make these quality markers mandatory. Therefore, we strongly encourage regions to take an active interest and supportive role in this area. What is to be done if a PCT does not prioritise this work?

7. We also recognise that the quality markers are not the “be all and end all” of ways to improve care for people with advanced respiratory disease. What will make the biggest difference is strong clinical leadership and whole systems working. We would expect that PCTs demonstrating the World Class Commissioning competences of collaboration with clinicians, and managing knowledge would make the most progress. We would also expect that SHAs have an important role in monitoring the performance of PCTs against these competences.

All diagnoses, including non-cancer

8. There are several references in the document to the need for the services to cover **all diagnoses**, which we welcome. From a respiratory perspective, the annual number of deaths from lung cancer and from advanced chronic obstructive pulmonary disease (COPD) are relatively similar (NICE 2004 data: COPD deaths UK 30,000, Cancer UK 2006 data: 34,150 lung cancer deaths), but people with COPD have symptoms which are more severe than lung cancer and which they suffer for longer, but are supported by fewer services at the end of their life [Gore, Edmonds et al 2001 Palliat Med 2001;15(4):287-95. and Gore JM, Brophy CJ, Greenstone MA. How well do we care for patients with end stage chronic obstructive pulmonary disease (COPD)? A comparison of palliative care and quality of life in COPD and lung cancer. Thorax 2000; 55: 1000-6]. Given the current inequity, the experience of respiratory-interested professionals suggests that there may need to be proportionately more emphasis on non-malignant disease to ensure that the end of life strategy encompasses all diagnoses. This approach recognises trends in incidence of cancer and non-cancer deaths. According to the National Audit Office, in 2020 COPD is expected to be the third largest cause of mortality in the western world. Currently in the UK there are almost 900,000 patients suffering from COPD and half as many more as yet undiagnosed. Patients dying from COPD have a heavy symptom burden of both physical and psychological suffering, not only from disabling breathlessness but also from pain, anxiety and depression, all of which are poorly addressed. Meanwhile between 1996 and 2005 male lung cancer incidence rates decreased by a fifth (21%). Over the same period there was little change in the female rates. For males and females combined the lung cancer incidence rate decreased by 11%. http://info.cancerresearchuk.org/cancerstats/types/lung/incidence/?a=5441

Different illness trajectories

9. The nature and end-stage of those with respiratory failure due to interstitial lung disease and motor neurone disease usually differ from those with COPD.

10. It is important to recognise that there are patients with different illness trajectories as shown in the Scottish policy Living and Dying Well: A national action plan for palliative and end of life care in Scotland: http://www.scotland.gov.uk/Publications/2008/10/01091608/3. (See Appendix 1) For example in organ failure such as COPD, death can appear ‘sudden’ against a background of inexorable decline, often during an exacerbation or due to co-morbid cardiovascular disease. A service designed for cancer may not be appropriate. Firstly, it is much harder to make a prognosis. Secondly, an acute admission for an exacerbation may be appropriate for end-stage COPD but is less likely to be appropriate for end-stage cancer. To quote the recent National Audit Office commissioned report from Rand Corporation “Page 20 “*Another factor may be the unpredictability of death. Organ failure tends to cause long-term lack of reserve, making the timing of death unpredictable. Faced with great uncertainty, it is more likely that more invasive medical treatment is used.“*

Registers (proposed as a marker in paragraphs 10 and 1.3.5, 1.4.2 , 1.4.3 and 1.4.4, 2.3 and 3.7)

11. We agree that we should be aiming for registers and systematic and timely sharing of information between primary care, out of hours services, ambulance services, care homes and hospitals. We agree that there are significant deficits in care at present, some of which might be overcome if information was shared more systematically. Many of the IMPRESS respondents quote examples where patients’ dignity was significantly compromised.

    “I couldn’t agree more with [ ] comment about the dignity offered to the severely demented patient, having seen elderly frail severely demented patients shipped back and forth from nursing homes just to bring their serum sodium down from 165 with some IV water!”

    “Many people at the end of life are unceremoniously dumped into hospitals by accessing OOH services inappropriately, even on the same day that measures have been taken by the primary care team in order to ensure an easy transition for the last days/hours of life.”

    “I too ……… some of my patients moved at night, from residential home (stuck on protocols) to out of hours (understaffed and without knowledge of patients) or paramedics (no knowledge of patients, protocol driven) to accident and emergency - and onwards”

Build on what exists

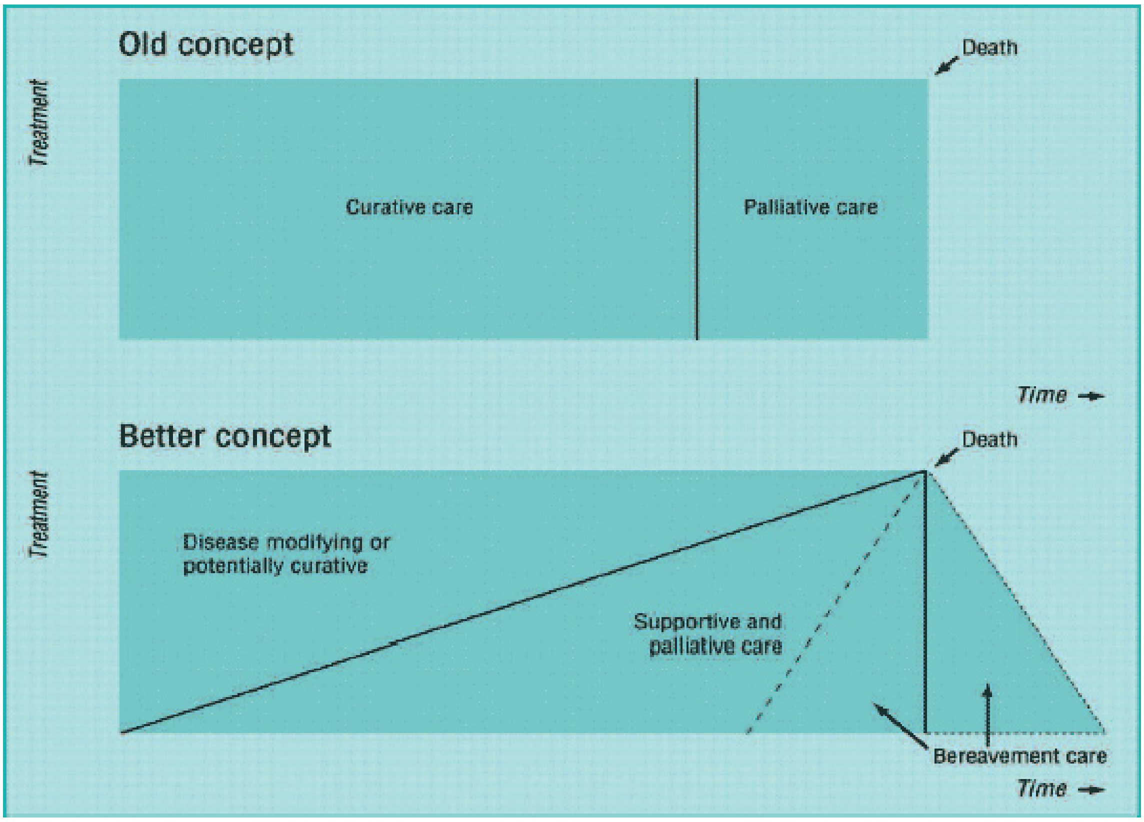
12. We regard the development of registers as an important contribution to patient care. Primary care registers are now well-established. The information technology is available as PCTs already hold lists of all addresses; in many places information is already transferred to out of hours services for patients in the last few days of life and some ambulance services have patient-specific protocols (the London Ambulance Service has a useful example). However, this information is often not systematically transferred to hospitals and is not currently tested in patients with advanced chronic respiratory problems.

The implications of an uncertain prognosis

13. However, there are also some essential differences between caring for people with terminal diseases other than cancer which need to be drawn out more in relation to registers. The consultation document uses the National Council's definition of end of life care: "*care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support'.* There are very specific challenges in working with registers for people with COPD. Despite an awareness of risk factors for a poor prognosis, predicting life expectancy for individual patients with COPD is extremely inaccurate (the only long term condition where prognosis is *less* accurate is dementia). [Christakis NA, Escarce JJ, Survival of Medicare patients after enrolment in hospice programs N Eng J Med 1996; 335: 172-8]. Fifty percent of people after an admission with acute respiratory failure in COPD (a key marker for inclusion on a palliative care register) will be dead in two years; it follows that 50% will be alive in two years. [Connors AF, Dawson NV, Thomas C, Harrell F, Desbiens N, Fulkerson WJ et al. Outcomes following acute exacerbation of chronic obstructive lung disease. The SUPPORT investigators Am J Respir Crit Care Med 1996; 154 (Pt 1):959-67 and Almagro P, Calbo E, Ochoa de EA, Barreiro B, Quintana S, Heredia JL, et al. Mortality after hospitalization for COPD. Chest 2002 May;121(5):1441-8]. It is thus not at all clear at what point the patient should go on a register. It is not known whether the all-embracing palliative care package is always appropriate. People at advanced stages of COPD may survive many years with a range of severe symptoms in need of palliation: they may need supportive care but not necessarily a full palliative care package including (for example) decisions about funeral arrangements [marker 1.3.4]. Perversely, the need to discuss and agree full palliative care packages may put off some clinicians and some patients from going on a register. Flexibility may be needed in the implementation of registers. We must avoid the situation where people are denied the supportive care that they need because they are not on a register. In addition, if someone is not on a register, and does not get the care from which they might have benefited, there must be an audit process to ensure the system learns how to do it better next time.

No clear cut transition from supportive care to palliative care

14. The supportive care needs of patients with advanced disease create a significant demand on service providers and are much larger than just a focus on the people with COPD who are dying. However, these two stages are not easy for a practising clinician and patient to identify. The transition to palliative care is particularly unclear in COPD. This is shown in model used in the Scottish policy Living and Dying Well: A national action plan for palliative and end of life care in Scotland: http://www.scotland.gov.uk/Publications/2008/10/01091608/2



Murray S, Kendall M, Boyd K and Sheikh A. Illness trajectories and palliative care. BMJ 2005 4; 330; 1007-1011 doi:10.1136/bmj.330.7498.1007 (Adapted from Lynn and Adamson, 2003. 5 With permission from RAND Corporation, Santa Monica, California, USA

Further challenges to decision-making

15. Finally, the decision-making of patients on the register may be more nuanced than those with other conditions. For example, they may not wish to be resuscitated or intubated but may want to be admitted and be considered for non-invasive ventilation (NIV) and this can be a source of confusion.

16. Furthermore, experience of our hospital colleagues is that patients with severe COPD in general have poor understanding of resuscitation and DNAR decisions (which is generally badly explained by medical staff) despite repeated admissions to hospital and the same is true of knowledge about NIV. Thus decision-making for COPD patients may not only be complex, but also poorly informed. These information gaps may need to be filled in order to empower patients, eg with provision of leaflets and education for patients with a view to empowering their participation in the decision-making process. Perhaps some sort of imperative for provision of this information could be added to the markers? We attach an example.

17. The complexity of decision making for this group is an issue for health professionals as well. We recommend the Royal College of Physicians (RCP) and British Thoracic Society (BTS) 2008 Concise guideline No 11 on Non-invasive ventilation in chronic obstructive pulmonary disease (http://www.rcplondon.ac.uk/pubs/brochure.aspx?e=258) which is a very logical and practical approach to this issue. Patient groups 3-5 are those in particular whose needs are being addressed in this document.
    (1) requiring immediate intubation and ventilation
    (2) suitable for NIV and suitable for escalation to intensive care treatment/ intubation and ventilation if required
    (3) suitable for NIV but not suitable for escalation to intensive care treatment/ intubation and ventilation
    (4) not suitable for NIV but for full active medical management
    (5) palliative care agreed as most appropriate management.

18. There is little mention of provision of support for patients to make formal Advance Directives or appoint a LPA (not an easy thing to do practically speaking) or for updating wishes with regard to end of life care, and no quality markers for this. Given the unpredictable prognosis for COPD, and often prolonged survival (even after severe, life threatening exacerbations), wishes frequently change over time (and

more than once). A decision, for example, never to be intubated again after a traumatic admission to ITU, may well be reversed 6 months down the line when the patient has survived and regained a stable quality of life. Therefore recorded decisions may need to be discussed again to make sure they are still valid. It is not uncommon for a patient who has made a decision about end of life care, to be admitted by a non-specialist team which then assumes that if the decision recorded in the notes was made by a specialist, that this is the correct decision, and do not discuss further with the patient.

Ask the patient

19. Given that determining an accurate prognosis by clinicians is difficult in COPD, the point at which someone might be included on a register is much less straightforward and requires even greater communication skill and coordination. One proposal is that the patient and carer(s) should be asked if they want to be on the register. Perhaps the pilots planned for January would ensure that people with COPD are included? There is also a need to ensure that those patients with comorbidities are known to all those likely to care for them in the advanced stages of their disease eg someone with end-stage lung cancer who has an exacerbation of COPD.

Significant event audit

20. We would also argue that in performance management terms, if there is a failure to enter appropriate information onto the register, the responsible organisation will initiate a significant event audit and establish processes to prevent a recurrence (a process overall assured by a regional managed care network for end of life care).

Care homes must have registers

21. Those responsible organisations might include community hospitals (part 4) and care homes (part 5) – therefore they too should share registers *not just* record preferences in their own notes (4.2 and 5.2). There was considerable concern expressed during our consultation about the inappropriate use of hospitals by patients sent from care homes. It is therefore crucial that care homes document, review and understand their residents' end of life plans and wishes. Our proposal, which would require the Department of Health to confirm its legality with its lawyers is: *" In cases where the resident has been determined as lacking capacity for decision-making there should, wherever possible, be formal documented agreement between the responsible medical staff and next of kin/power of attorney with regard to resuscitation status. If no agreement is possible, the ultimate decision would rest with the responsible medical team."*

Coroners

22. We would also argue that it is important to involve another key stakeholder – the local coroner. There needs to be a common goal and understanding about high quality end of life care for people with COPD between the coroner, hospitals and care homes particularly following the Shipman enquiry.

Potential for research/piloting and evaluating

23. An approach that some local systems may wish to test, or could be piloted, would be to segment the population according to its likely disease trajectory. An alternative would be a two stage process:
    <u>Stage 1 of a two-stage process</u> Registers for people with "advanced" COPD who are at risk of dying because they have one or more disabling symptoms that need palliation. We recommend the term "advanced" rather than "very-severe" because the latter could be confused with Global Initiative on Obstructive Lung Disease (GOLD) stages. So all those with (say) an admission for COPD, or with MRC dyspnoea score 5, or with chronic hypoxia would be on this list. This would flag the need for a multidisciplinary approach, and a focus on symptom control, which might included NIV, but importantly it would have no implications for expected survival. Whilst advance care plans may be appropriate for some of these patients there would no expectation that everyone on this list would have DNAR status, preferred place of death etc. recorded.
    <u>Stage 2 of a two-stage process</u> End-of-life COPD register for patients where advanced planning is particularly appropriate (eg after NIV/ventilation for an episode of respiratory failure where future preferences are crucial, such as resuscitation and NIV, or those with multiple co-morbidity) or if the patient wishes to discuss advance plans. Their supportive care needs should already be documented and they are likely to be a palliative care pathway.

24. Please note that 1.3.5 *Ensure entry onto a locality-wide end of life care register, if available* conflicts slightly with 1.4.2 *A locality-wide register of patient approaching the end of life is maintained.* These

need to be consistent.

Registers and access to care

25. While registers form an important aspect of identifying patients requiring intensified care and management, the day-to-day concern of patients with severe COPD is how to access a known health care professional or team (other than the ambulance service!) for symptom control and exacerbation management, even if only by telephone. Section 1.5.1 of the consultation document, is a welcome recognition of the need for 24/7 essential services to enable people to live and die in their place of choice. However, for COPD, this requirement may last for many months or years. If the registers result in formal provision of care that is easy for the patients to access (not just for dying, but rather more importantly, for living), they will have been a useful maker of quality. Documentation of clear and accessible care/contact pathways for COPD patients on registers would be an even more useful marker of quality.

26. Therefore, if these points are agreed, this would suggest some specific additions to the following clauses (*in italics*):

1.3 Identification, communication and care planning
PCTs to demonstrate that all providers have processes in place to:
1.3.1- 1.3.4 Identify those approaching the end of life*, the likely trajectory of illness and needs for care appropriately discussed.*

1.3.5 Ensure entry onto end of life register *recognising that the content and detail in COPD patients is likely to be different from those with cancer. Decision-making may also be more complex eg wish not to be resuscitated or intubated but may wish to receive non-invasive ventilation (NIV).*

We suggest the addition of a further marker about provision of high quality information and education for patients about decisions relating to DNAR, intubation and NIV. We attach an example.

We also suggest the addition of a marker about provision of support to patients to make formal Advance Directives or to appoint a lasting power of attorney (LPA).

1.4 Coordination across boundaries *but also across longitudinal aspects of care eg. supportive care to end of life care*

Add: Focus on care differences according to trajectory of illness in addition to setting of care. Recognise that trajectories within a diagnosis eg respiratory failure, may be very different in those with COPD, interstitial lung disease or motor neurone disease

Availability of services
1.5.1 Measure: documentation regarding community services and the proportion of the local population covered by these services.
Suggest addition: Documentation of clear and accessible care/contact pathways for COPD patients on registers.

Part 3: Quality markers for acute hospitals
3.4 They have effective mechanisms for identifying those who are approaching the end of life. *Here trigger points are needed and should be more explicit eg. hypercapnic exacerbation requiring non invasive ventilation (NIV), onset of cor pulmonale etc*

Quality markers for out of hours medical services
9. Complexity of out of hours care – *patients may wish to be admitted and to have NIV but not resuscitation as per 1.3.5*

Education, Training and Audit

Communication skills

27. We agree that **education and training**, particularly on communication are essential: points 1.8.2, 3.14, 4.9, 5.9, 6.8 and 7.7. IMPRESS will launch, by the end of February 2009, an educational package for clinicians on communication about diagnosis and end of life care for people with COPD, funded by the Department of Health COPD Clinical Strategy team called Effective Care – Effective Communication: Living and Dying with COPD. This contains videoed interviews of patients and carers describing their experience, an expert panel discussion, and sets of PowerPoint slides with teaching notes. We would hope that this might be offered to PCTs as a resource. There should be an equivalent marker in section 9 on out of hours services. Also in section 9 there should be a responsibility to engage in significant event audit (eg 9.3 should also mention significant event audit).

Stories

28. One of the challenging aspects of care is how to communicate the different illness trajectories to the public and patients. Whilst not suitable for a quality marker, it could be an aspect of local discussion to ensure consistent messages by different professional groups. For example, Joanne Lynn advocates story telling and a different use of language.[Joanne Lynn, "Living Long in Fragile Health: The New Demographics Shape End of Life Care," Improving End of Life Care: Why Has It Been So Difficult? Hastings Center Report Special Report 35, no. 6 (2005): S14-S18 http://www.thehastingscenter.org/uploadedFiles/News/News_Stories/Living_Long_in_Fragile_Health.pdf

Symptom management of breathlessness and other symptoms

29. We believe that there is insufficient **expertise** within many existing palliative care teams, hospice teams and in primary and secondary care in the management of breathlessness and the other symptoms of diseases as COPD and interstitial lung disease. Therefore when expertise is described as important at 1.5.4 and 7.2 and in the hospice section 6. for example, this should include expertise in managing people with conditions such as COPD, and the symptoms associated with advanced disease, specifically breathlessness. So, if a patient was on a register, this would equate to the first stage of the two-stage process we describe. This is important because the examples in the document eg 9.2 and 9.4 tend to focus on drugs and emergency medication. This might lead commissioners to ignore non-pharmacological interventions which are crucial in managing breathlessness:
    Breathing training
    Walking aids
    Neuromuscular electrical stimulation
    Chest wall vibration
    Hand-held fan
    Anxiety management
    Physiotherapy

We also recommend that advice about the use of oxygen in palliative care should be consistent with the forthcoming home oxygen guidelines (i.e in the presence of hypoxaemia).

Breathlessness references:

Bausewein C, Farquhar M, Booth S, Gysels M, Higginson IJ. Measurement of breathlessness in advanced disease: A systematic review. Respir Med 2006 Aug 14.

Bausewein C, Booth S, Gysels M, Higginson I. Non-pharmacological interventions for breathlessness in advanced stages of malignant and non-malignant diseases. Cochrane Database Syst Rev 2008;(2):CD005623.

Booth S, Farquhar M, Gysels M, Bausewein C, Higginson IJ. The impact of a breathlessness intervention service (BIS) on the lives of patients with intractable dyspnea: a qualitative phase 1 study. Palliat Support Care 2006 Sep;4(3):287-93.

Booth S, Moosavi SH, Higginson IJ. The etiology and management of intractable breathlessness in patients with advanced cancer: a systematic review of pharmacological therapy. Nat Clin Pract Oncol 2008 Feb;5(2):90-100.

Summary

30. In summary, answering the three specific points of the consultation:

1. Will these quality markers be useful to commissioners, performance managers and service providers?

Yes, if

- There is strong SHA leadership to ensure it is considered as a local priority both in order to meet the Commissioning Vital Sign for end of life care, and to ensure that there are comprehensive services in place for people with long term conditions.
- There is briefing and awareness-raising accompanying them, particularly with regard to non-malignant diseases, different disease trajectories and the specific issues related to COPD.
- The significant event audit is used, as proposed above.
- It encourages local discussion about what is needed locally to support the improvement in end of life care, for example the prompt sharing of information and more education and training on symptom management and on communications with patients and carers. We have offered a training package to be part of that.
- There are any data protection issues regarding registers central guidance is provided.
- A repository of the evidence can be established. For example, we have included a number of references and highly recommend a recent review of the evidence: Palliative and end-of-life care for patients with severe COPD. Curtis J. R. Eur Respir J 2008 (Sept); 32: 796-803

2. Do the suggested quality markers cover the right aspects of end of life care provision? Should some of them be removed or others added?

- Yes, but there needs to be greater consistency, so that the different service providers all have responsibility for using the register, and for education, training and audit.

- We have proposed two additions in relation to supporting informed decision-making. We enclose examples of leaflets for patients.

- There is no specific mention in the document about the value of an *integrated* approach across health and social care, across primary and secondary care and across specialties and with patients or patient representatives. This has been shown to work well in the management of HIV patients and other conditions. One example quoted during the consultation was of a motor neurone disease multidisciplinary group including palliative care, neurology and respiratory consultants, community workers and representatives from the Motor Neurone Disease society.

For example, we would suggest

3.2 They have a multi disciplinary specialist palliative care team. *Please note it is also really important for palliative care to take part in multidisciplinary respiratory teams.*

3. Are the identified measures fit for purpose? Should any others be included?

- Our comments are listed above particularly in relation to disease trajectories, prognosis and registers.

- It may be appropriate to look at a much more generic marker of support and investment by PCTs to empower and enable clinicians to improve their communication with patients and others in the system.

- We suggest strengthening the quality markers that relate to care homes. See above and also note our point in relation to coroners.

- This is an evolving field of research and therefore there is no evidence at present for other markers. However, we would hope they can be amended in the light of future evidence.

We hope you find these comments helpful.

Yours sincerely

Dr Anthony Davison

Co-chair IMPRESS

Dr Steve Holmes

Co-chair IMPRESS

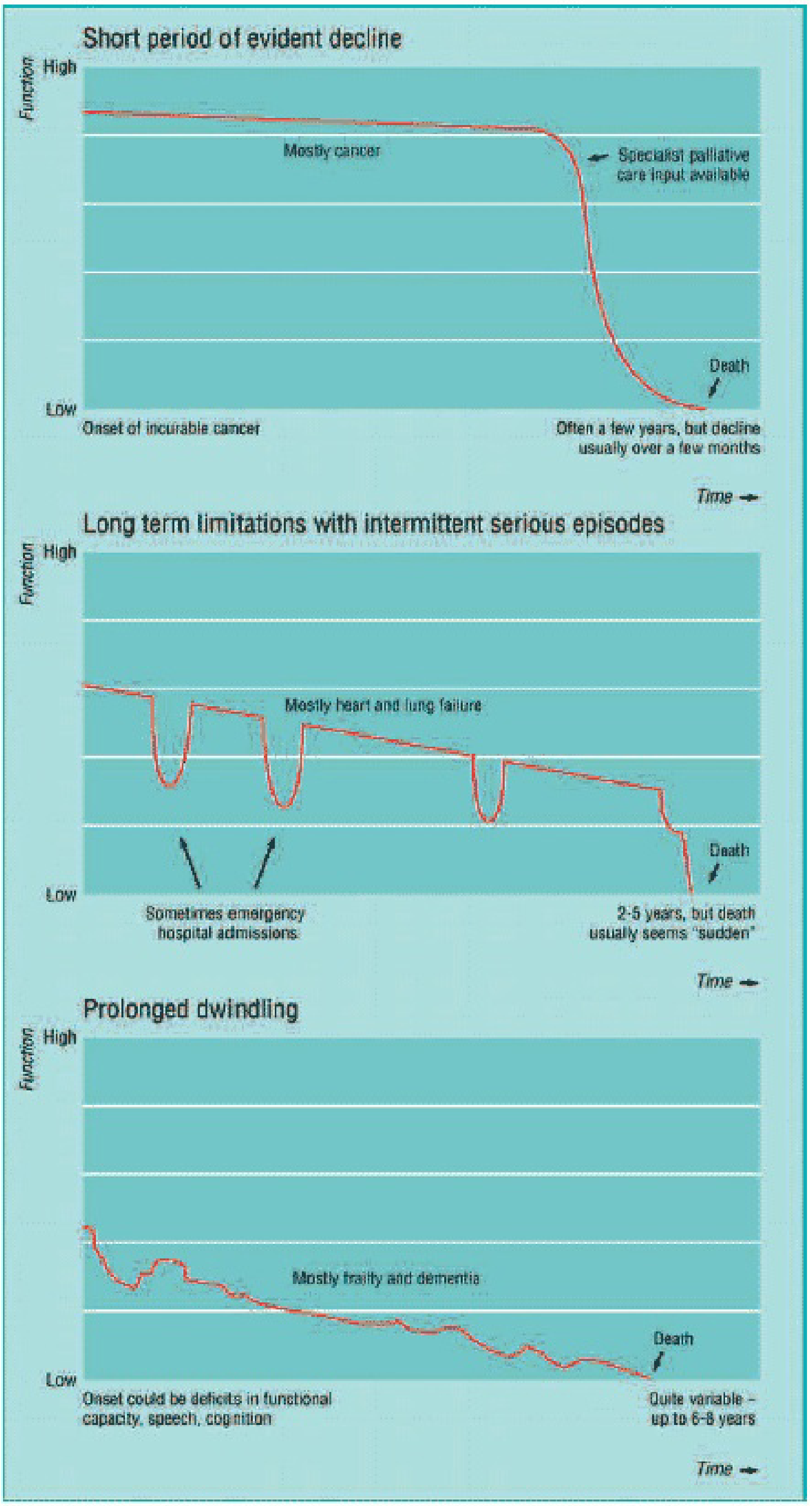
Enclosures:

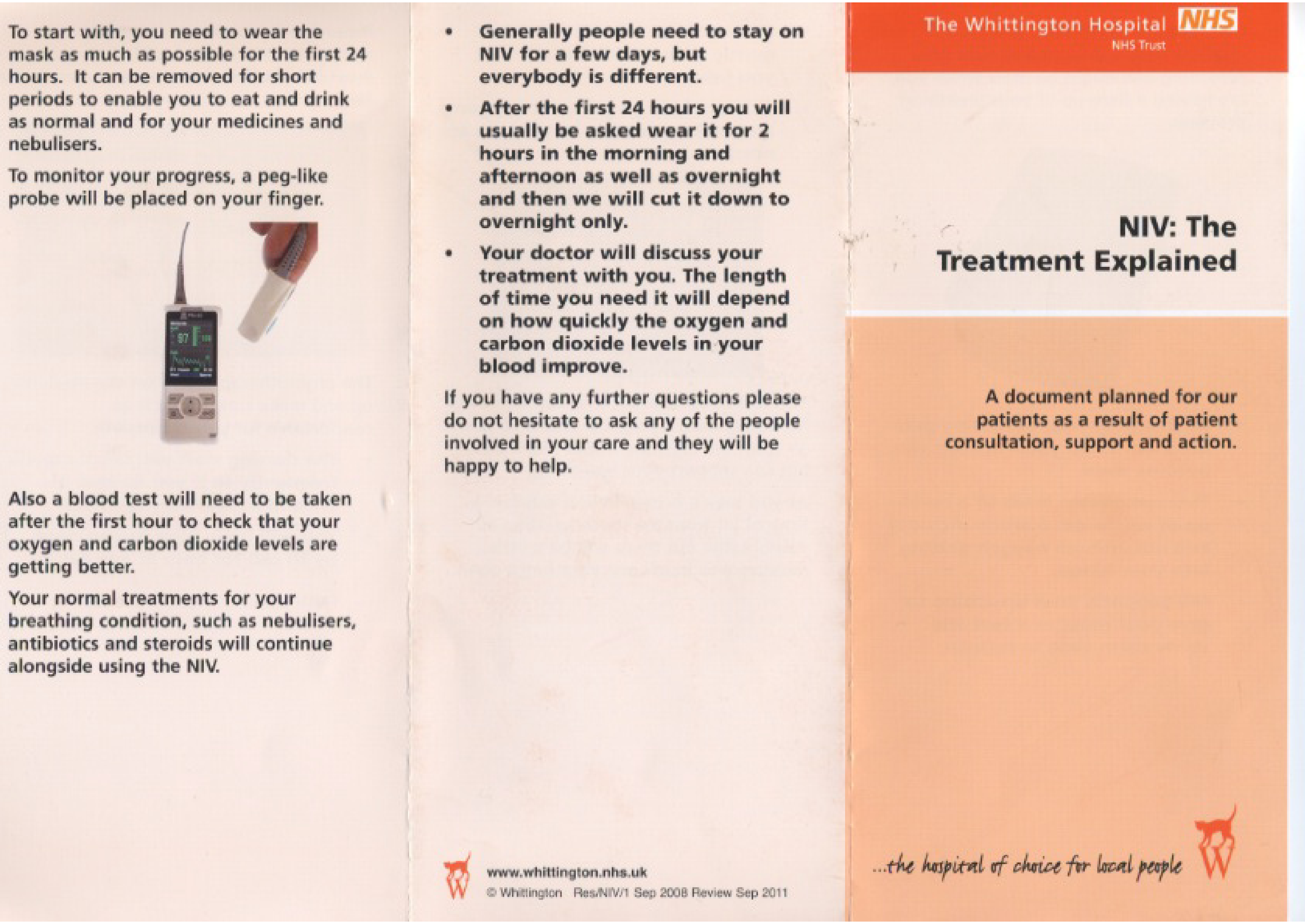
Patient information leaflet: Resuscitation. What it means and your role in making a choice

Patient information leaflet: NIV: the treatment explained

APPENDIX 1

Illness trajectories taken from http://www.scotland.gov.uk/Publications/2008/10/01091608/3 Murray S, Kendall M, Boyd K and Sheikh A. Illness trajectories and palliative care. BMJ 2005 4; 330; 1007-1011 doi:10.1136/bmj.330.7498.1007. Reproduced with permission from BMJ Publishing Group Ltd and RAND Corporation,Santa Monica this)California, USA





To start with, you need to wear the mask as much as possible for the first 24 hours. It can be removed for short periods to enable you to eat and drink as normal and for your medicines and nebulisers.

To monitor your progress, a peg-like probe will be placed on your finger.

Also a blood test will need to be taken after the first hour to check that your oxygen and carbon dioxide levels are getting better.

Your normal treatments for your breathing condition, such as nebulisers, antibiotics and steroids will continue alongside using the NIV.

- **Generally people need to stay on NIV for a few days, but everybody is different.**
- **After the first 24 hours you will usually be asked wear it for 2 hours in the morning and afternoon as well as overnight and then we will cut it down to overnight only.**
- **Your doctor will discuss your treatment with you. The length of time you need it will depend on how quickly the oxygen and carbon dioxide levels in your blood improve.**

If you have any further questions please do not hesitate to ask any of the people involved in your care and they will be happy to help.

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NIV: The Treatment Explained

A document planned for our patients as a result of patient consultation, support and action.

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Non Invasive Ventilation (NIV) is a machine that is designed to help your breathing and might be used when you are having a flare-up of your breathing problem.

- **At this time your breathing gets hard work and your muscles can become tired.**
- **This sometimes leads to a build-up of waste gas (carbon dioxide) and not enough oxygen getting into your blood.**
- **NIV supports your breathing to give your muscles a rest and allow them time to recover.**
- **It doesn't breathe for you, but gently assists each breath that you take.**
- **This can help to get your oxygen and carbon dioxide levels back to normal.**

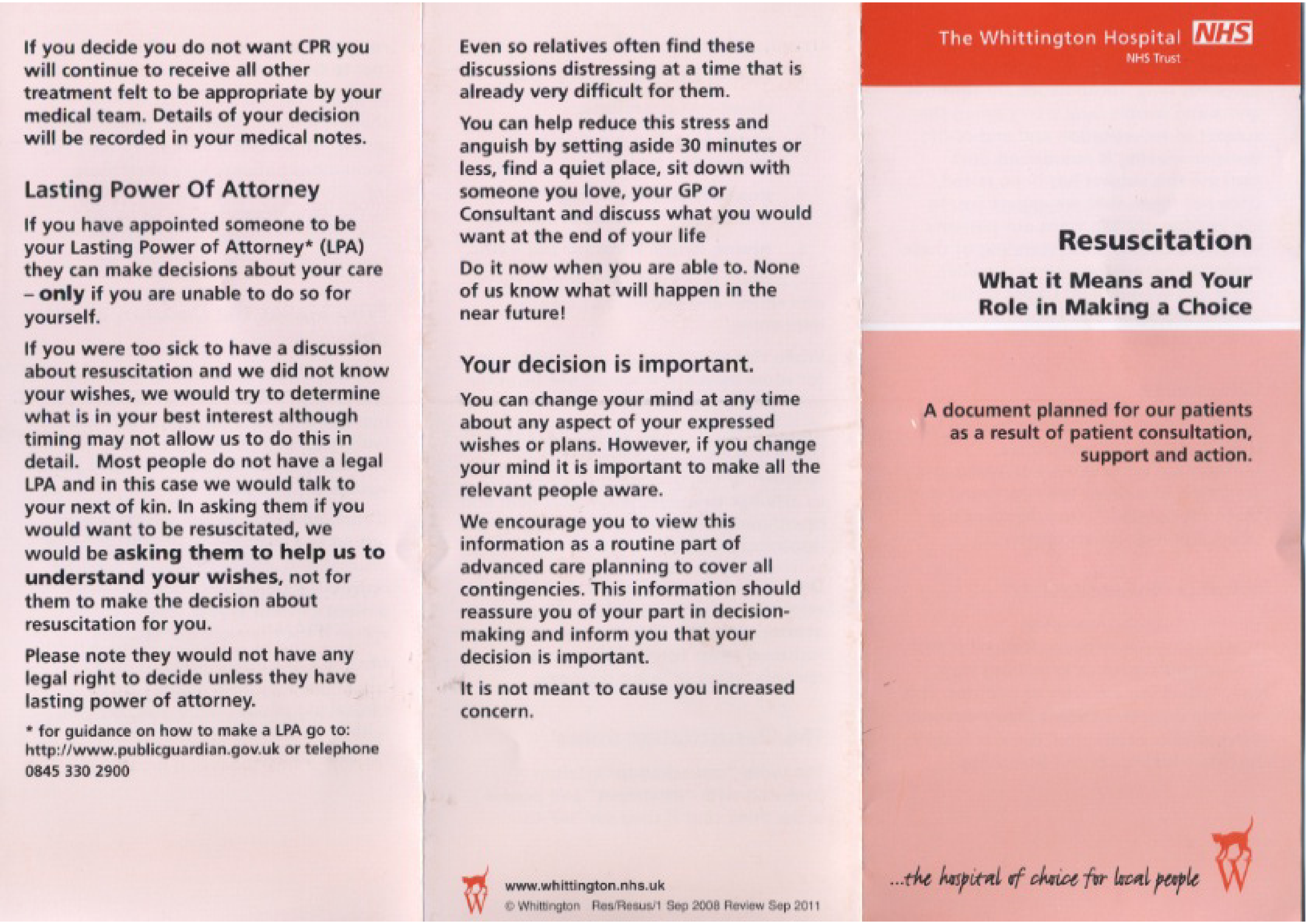
You will need to wear a facemask, which fits firmly but not tightly. This is so the air from the machine doesn't leak out but can support your breathing.

As you take a breath in you will feel a flow of air from the machine, then as you breathe out there will be a little resistance to help keep your lungs open.

It can feel a bit strange or even uncomfortable to start with, however most people find that they get used to it fairly easily.

The physiotherapist will set the machine up and make sure that it is as comfortable for you as possible.

- **The nursing staff will check on you frequently so if you do find it uncomfortable they can help.**
- **You will have your buzzer near by to call for help at any time.**



If you decide you do not want CPR you will continue to receive all other treatment felt to be appropriate by your medical team. Details of your decision will be recorded in your medical notes.

Lasting Power Of Attorney

If you have appointed someone to be your Lasting Power of Attorney* (LPA) they can make decisions about your care – **only** if you are unable to do so for yourself.

If you were too sick to have a discussion about resuscitation and we did not know your wishes, we would try to determine what is in your best interest although timing may not allow us to do this in detail. Most people do not have a legal LPA and in this case we would talk to your next of kin. In asking them if you would want to be resuscitated, we would be **asking them to help us to understand your wishes,** not for them to make the decision about resuscitation for you.

Please note they would not have any legal right to decide unless they have lasting power of attorney.

* for guidance on how to make a LPA go to: http://www.publicguardian.gov.uk or telephone 0845 330 2900

Even so relatives often find these discussions distressing at a time that is already very difficult for them.

You can help reduce this stress and anguish by setting aside 30 minutes or less, find a quiet place, sit down with someone you love, your GP or Consultant and discuss what you would want at the end of your life

Do it now when you are able to. None of us know what will happen in the near future!

Your decision is important.

You can change your mind at any time about any aspect of your expressed wishes or plans. However, if you change your mind it is important to make all the relevant people aware.

We encourage you to view this information as a routine part of advanced care planning to cover all contingencies. This information should reassure you of your part in decision-making and inform you that your decision is important.

It is not meant to cause you increased concern.

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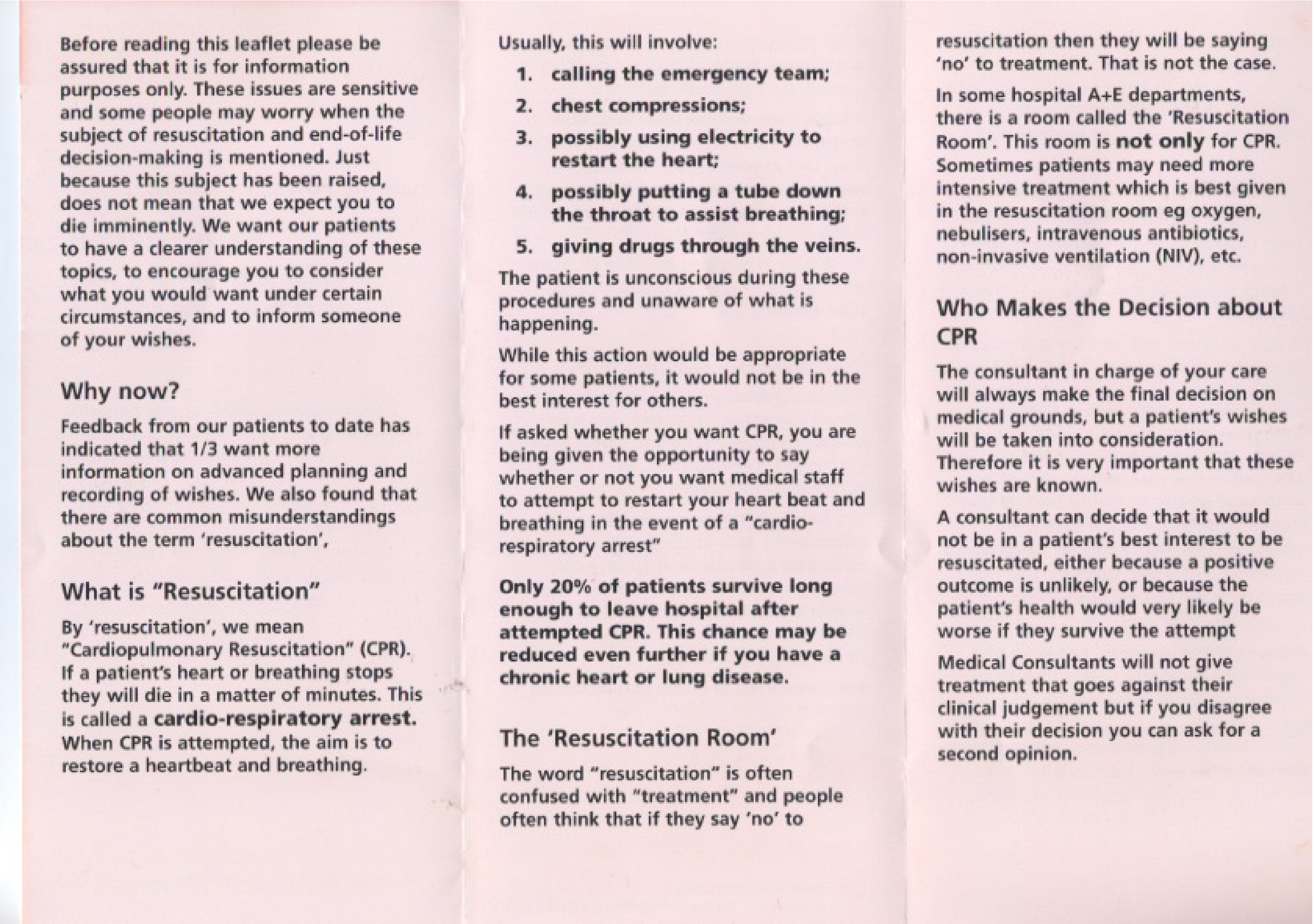
Resuscitation

What it Means and Your Role in Making a Choice

A document planned for our patients as a result of patient consultation, support and action.

...the hospital of choice for local people



Before reading this leaflet please be assured that it is for information purposes only. These issues are sensitive and some people may worry when the subject of resuscitation and end-of-life decision-making is mentioned. Just because this subject has been raised, does not mean that we expect you to die imminently. We want our patients to have a clearer understanding of these topics, to encourage you to consider what you would want under certain circumstances, and to inform someone of your wishes.

Why now?

Feedback from our patients to date has indicated that 1/3 want more information on advanced planning and recording of wishes. We also found that there are common misunderstandings about the term 'resuscitation',

What is "Resuscitation"

By 'resuscitation', we mean "Cardiopulmonary Resuscitation" (CPR). If a patient's heart or breathing stops they will die in a matter of minutes. This is called a **cardio-respiratory arrest.** When CPR is attempted, the aim is to restore a heartbeat and breathing.

Usually, this will involve:

1. **calling the emergency team;**
2. **chest compressions;**
3. **possibly using electricity to restart the heart;**
4. **possibly putting a tube down the throat to assist breathing;**
5. **giving drugs through the veins.**

The patient is unconscious during these procedures and unaware of what is happening.

While this action would be appropriate for some patients, it would not be in the best interest for others.

If asked whether you want CPR, you are being given the opportunity to say whether or not you want medical staff to attempt to restart your heart beat and breathing in the event of a "cardio-respiratory arrest"

Only 20% of patients survive long enough to leave hospital after attempted CPR. This chance may be reduced even further if you have a chronic heart or lung disease.

The 'Resuscitation Room'

The word "resuscitation" is often confused with "treatment" and people often think that if they say 'no' to resuscitation then they will be saying 'no' to treatment. That is not the case.

In some hospital A+E departments, there is a room called the 'Resuscitation Room'. This room is **not only** for CPR. Sometimes patients may need more intensive treatment which is best given in the resuscitation room eg oxygen, nebulisers, intravenous antibiotics, non-invasive ventilation (NIV), etc.

Who Makes the Decision about CPR

The consultant in charge of your care will always make the final decision on medical grounds, but a patient's wishes will be taken into consideration. Therefore it is very important that these wishes are known.

A consultant can decide that it would not be in a patient's best interest to be resuscitated, either because a positive outcome is unlikely, or because the patient's health would very likely be worse if they survive the attempt

Medical Consultants will not give treatment that goes against their clinical judgement but if you disagree with their decision you can ask for a second opinion.