Palliative and End of Life Care Policy

for Scottish Ambulance Service staff (Revision 9.2)

Approved Version – 23 April 2014

Scottish Ambulance Service

and

Scottish Partnership for Palliative Care

Robin Lawrenson
Clinical Performance Manager
Scottish Ambulance Service
rlawrenson@nhs.net

Contents

Section 1: Glossary

ACC	**Ambulance Control Centre**
CPR	**Cardiopulmonary Resuscitation**
CYPADM	**Children/Young People Acute Deterioration Management**
DNACPR	**Do Not Attempt Cardiopulmonary Resuscitation**
KIS	**Key Information Summary**
SPCC	**Scottish Partnership for Palliative Care**
ACP	**Anticipatory Care Plan**
JRCALC	**Joint Royal Colleges Ambulance Liaison Committee**
OOH	**Out Of Hours (Service)**
PCA	**Patient Controlled Anaesthesia**
SAS	**Scottish Ambulance Service**

Section 2: Palliative Care

Introduction

For the purposes of this document, palliative care may be defined as: the total care of patients at a time when their disease is no longer responsive to curative treatment and when life expectancy is relatively limited. Some patients with palliative care needs requiring ambulance transport will have a prognosis of weeks or even days but it must be recognised that increasingly there are patients who are living for longer with their incurable and progressive illness but who still have great need for a palliative approach to their care. The needs of such patients include the basic and underlying needs of any patient, however there are added considerations and actions that must be adopted to ensure that the best possible care is given. This policy is intended to provide practical guidance to ambulance staff involved in the caring of, arranging transport for, and training staff in the needs of patients who have palliative care needs.

Aims

***When dealing with people who require palliative care and or end of life care, an Ambulance Service should aim to*:**

- work closely with other NHS and non-NHS disciplines
- deliver care that is tailored to each particular patient
- patients, wherever possible will be given the opportunity to be involved in decisions about their care to the extent that they want to be
- consider the needs and requests of the patient's family whenever possible
- ensure that arrangements are sufficiently flexible to ensure delivery to the appropriate location within agreed time frames
- provide patients with pain and symptom relief, maintenance of drug administration equipment, and positional support
- assist those important to the patient to manage dying and death, and support their immediate psychological needs, following approved policy for bereavement care.
- minimise time spent waiting for transport
- facilitate access to specialist care as appropriate
- minimise time spent in transit
- simplify ordering processes and respond rapidly to requests for transport
- comply where feasible with advance care preferences, eg chosen location for last days of life, DNACPR orders, CYPADM forms, advance directives, living wills.
- The key principles outlined within Scottish Government's *Interim Guidance – Caring for people in the last days and hours of life* offer valuable guidance –

Key Principle 1: *Informative, timely and sensitive communication is an essential component of each individual patient's care.*
Key Principle 2: *Significant decisions about a patient's care, including diagnosing dying, are made on the basis of multi-disciplinary discussion.*
Key Principle 3: *Each individual patient's physical, psychological, social and spiritual needs are recognised and addressed as far as is possible.*
Key Principle 4: *Consideration is given to the wellbeing of relatives or carers attending the patient.*

Requesting Transport for Patients with Palliative and/ or End of Life Care Needs

Health care professionals requesting transport through the Scottish Ambulance Service (SAS) should ensure that they are in a position to provide as much information as possible. A list of minimum requirements is included in Section 4 of this document. The priority level required should be decided purely on clinical need, and should be as flexible as is reasonably possible. If a patient is to be taken home to die, it is very important that the agreed timescale is followed – collection of the patient should be a maximum of 4 hours following the call unless agreed otherwise. Acc Despatch staff should do all that is possible to provide a response that matches the needs of the patient. Details of DNACPR/CYPADM orders must be communicated, along with advice on where any orders can be viewed, the period they cover, the patient's/family's knowledge of the order, and the circumstances to which they relate. The name and contact number of a senior clinician responsible for the patient, who can be contacted by the Ambulance Control Centre (ACC) for advice during the journey time, should be given.

Managing Transport for Patients with Palliative and/ or End of Life Care Needs

Ambulance Service staff responsible for despatch should be given all required information from clinicians whenever they are informed that the patient has palliative and/ or end of life care needs. In such instances, ACC staff should always ensure that, if any DNACPR/CYPADM orders are in place, operational staff are aware of this. If such an order is verbal, for example over the telephone, the senior clinician taking responsibility for that decision should always be noted. Further details can be found in Section 4.

Unless such patients are attending routine day care or outpatient clinics, they should be transported directly to their destination, and with no other patients unless absolutely necessary. Minimum facilities to be provided for such patients would include:

- ability for the patient to lie down if required
- oxygen equipment
- modesty requirements eg vehicle blinds
- staff trained in first aid, including resuscitation
- staff trained to deliver comfort and supportive measures as appropriate
- equipment and training sufficient to deal with pain and vomiting.

NHS Scotland has a national DNACPR policy that should be followed at all times. For children and young people, the relevant policy is Resuscitation Planning Policy for Children and Young Adults, and the resuscitation plan for children (which may instruct that full resuscitation efforts must be undertaken) will be found on the Children/Young People Acute Deterioration Management (CYPADM) Plan. Throughout this document, where DNACPR is referred to, this also applies to CYPADM for children/young people unless stated to the contrary.

Key Information Summary (KIS)

Whenever possible, access should be gained to the patient's KIS where one exists. It should be communicated to the attending crew that a KIS exists, otherwise automated transmission should be afforded. The aim is to ensure that crews are aware of any instructions (eg Advance Care Plans, DNACPR status) prior to arrival on scene.

Transporting and Caring for Patients with Palliative and/or End of Life Care Needs

For routine transfer of palliative care patients, operational staff should, prior to arriving on scene:

- ensure they know if they are instructed to attempt resuscitation in the event of a cardiopulmonary arrest
- ensure they know the exact location for collection and delivery of the patient
- ensure they know an alternative location for delivery should the patient with a DNACPR/CYPADM order die en route
- ensure they know whether the patient/family is aware of any DNACPR order (essential for patients being transported home).
- Sight of a written DNACPR/CYPADM form may be requested, but is not necessary if it is clear that this individual is taking clinical responsibility for the decision, and must never delay transport arrangements.
-

Detailed procedures for DNACPR/CYPADM orders are attached under Section 3. It must be stressed that, if there is any doubt concerning the existence of a DNACPR/CYPADM order for a patient who has a cardiopulmonary arrest, resuscitation must be attempted unless the crew are absolutely confident in their clinical judgment that Cardiopulmonary Resuscitation (CPR) would not be successful. Acute injury, acute illness, pain, vomiting, distress or any other sign/symptom are unaffected by DNACPR orders and must be dealt with as they arise. Similarly, unless a patient undergoes a cardiorespiratory arrest, the presence of a DNACPR has no relevance to that patients care or transport planning.

Patients with palliative and/ or end of life care needs have the same rights of any other patients. They must always be treated courteously and professionally, as should their families and carers. In addition, special care should be taken to ensure crews observe the following points:

- consent guidance, duty of care, human rights and the right of refusal apply to patients with palliative and end of life care needs exactly as they apply to all patients (refer to and comply with SAS Consent Policy).
- the patient's established wishes are given priority.
- the views of relatives and carers should be sought and catered for whenever it is feasible to do so
- minimum time possible in transport and handover
- patient confidentiality guidance must be strictly adhered to (refer to and comply with JRCALC 2013 Patient Confidentiality Guideline)
- if a senior clinician (doctor or nurse) with clinical responsibility for the patient advises in person or by telephone that resuscitation is not to be attempted, this should be respected.

For urgent/emergency transfer of patients with palliative and or end of life care needs, the general rules outlined above apply. In addition, special care should be taken to ensure:

- pain and symptom relief is offered as appropriate, and existing medication taken into account
- the views of relatives and carers should be sought and catered for whenever it is feasible to do so as long as it is clear that the patient's established wishes are given priority.
- a large degree of flexibility must be used to ensure that any relatives/carers who wish to escort the patient can do so. In such circumstances, there is no set limit on the number of escorts as long as the number complies with the safe seating and legal requirements of the vehicle
- all care delivered by SAS staff must be fully documented and communicated to the receiving clinicians
- if there is uncertainty over whether a DNACPR/CYPADM order exists, resuscitation should be attempted unless it is absolutely clear that the patient is in the terminal phase of illness and resuscitation will not be effective. In the emergency situation clinical judgement should be used to decide on what, if any, advanced life-support measures to offer, always acting for the wider benefit of the patient
- in the case of death of a patient with a DNACPR order en route, the patient should be transported to the destination on the ambulance section of the DNACPR and ACC contacted. Where resuscitation was not attempted due to reasons given above, ACC should be requested to seek guidance from the clinician responsible for the patient. If advice cannot be gained, the patient should be taken to the nearest mortuary and ACC should be requested to inform the police – unless alternative local arrangements are in place.

Children and Young People

It is likely that ambulance clinicians will only be involved in considerations of resuscitation for children and young people in emergency settings. The principles outlined within this document that refer to adults also apply to children and young adults, and where DNACPR/CYPADM is noted, the advice should be applied for all age groups.

In the event of an unpredicted emergency situation where the issue of resuscitation has not been previously considered there is a presumption that full and active resuscitation will take place until the child's lead consultant makes a decision based on the best clinical judgement at that time.

If a resuscitation plan has been agreed for a child/young adult, a Children/Young People Acute Deterioration Management (CYPADM) form will have been completed. It is not necessary that this form is seen by ambulance clinicians, however it should be shown if possible. This form is valid if it has been signed by a senior clinician. The CYPADM form is designed to be a patient/ family held document unless the patient is an inpatient, and should be with the patient at all times.

It must be noted that the CYPADM form is **NOT** a DNACPR form. Its existence does not suggest that a patient should not be resuscitated. Instead, it gives instructions on how to manage an episode of acute deterioration which may include a cardiac or

respiratory arrest. The form must be studied, or instructions clearly communicated in advance of transportation, to discover the actions that may be required in an emergency situation.

Children/young people must continue to be assessed, managed and receive treatments that are appropriate for their health and comfort irrespective of their resuscitation status.

In the home setting, there may be particular circumstances when a CYPADM form is known to exist, yet family/carers cannot accept that CPR will not be attempted. In such difficult and unusual circumstances, it may be that CPR could be carried out within a conflict resolution context. Although clinicians can not be coerced into providing futile, ongoing measures, ambulance clinicians would be supported in such instances.

It should be noted that the CYPADM form indicates the treatments that should be offered in the event of a cardiopulmonary arrest, and not those that should be withheld.

Section 3: DNACPR (Do Not Attempt Cardiopulmonary Resuscitation)

Introduction

There is moral and legal consensus about the right of patients to refuse treatment. This becomes more complex when the patient cannot express their views. Similarly, no patient can demand treatment that is likely to be ineffective. In order to clarify these areas in the event of cardiac arrest, guidance exists that is intended to prevent inappropriate, futile and/or unwanted attempts at CPR that may cause significant distress to patients and families, as a death with an inappropriate CPR attempt may be undignified and traumatic.

This section is intended to provide practical guidance to Scottish Ambulance Service staff when dealing with patients who are the subject of a DNACPR order. It should be read in conjunction with existing guidelines on Resuscitation Planning Policy for Children and Young Adults, Consent, Vulnerable Persons, Patient Confidentiality and AACE/JRCALC 2013 Clinical Guidelines. This advice is intended to complement, and does not override, the advice given in NHS Scotland's National DNACPR Policy for adults and Resuscitation Planning Policy for Children and Young Adults.

Definition

Ambulance staff will be notified that there is a DNACPR/CYPADM order for a patient in one of four ways:

1. they will see a completed DNACPR/CYPADM form (see Section 5)

2. they will receive a signed letter from a doctor/senior nurse, handed to them when they pick up the patient
3. they will be informed by telephone by a senior clinician (doctor or nurse) with responsibility for the patient, that resuscitation should not be attempted
4. they will access the patient's palliative care record (KIS or ePCS) where DNACPR/CYPADM instructions are noted.

Presumption in favour of CPR where there is no DNACPR/CYPADM decision

When no explicit decision has been made about attempted resuscitation before a cardiopulmonary arrest, or ambulance clinicians are uncertain whether a DNACPR/CYPADM order is in place, they should assume that no such order exists and use their clinical judgement to provide full clinical care as appropriate. In such emergencies there will rarely be time to make a proper assessment of the patient's condition or the likely outcome of CPR and so attempting CPR will usually be appropriate.

However there will be some patients for whom attempting CPR is clearly inappropriate; for example a patient who is known to be in the final stages of a terminal illness where death is imminent and unavoidable and CPR would not be successful, but for whom no formal DNACPR /CYPADM decision has been made. In such circumstances, ambulance clinicians who make a considered decision not to commence CPR would be supported by their senior colleagues and employers.

Patient History

Prior to any journey, it is the duty of the carer/clinician responsible for the patient to allow SAS staff to see, or to communicate the existence of any DNACPR/CYPADM form that is in place, and that:

1. patient details are clear and correct on the form
2. the DNACPR/CYPADM form has been signed by the responsible senior clinician (doctor or nurse). A junior doctor or senior nurse may also sign the form and indicate that a GP or consultant has taken responsibility for this decision
3. the Ambulance Crew Instructions section of the form states who to contact and where to take the patient if they die in the ambulance
4. the crew should be informed whether the patient and family are aware of the DNACPR/CYPADM form:
    - if the form is going home with the patient the patient and family ***must be*** aware of the form – do not leave the form in the patient's house unless this is certain. Where the patient/family is not aware of the DNACPR/CYPADM order it should not go with the patient.
    - patients being transferred between hospitals or to hospice or care home may have a DNACPR form without having had specific discussion about this because a judgment has been made that such discussion would cause harmful distress for the patient.. In this circumstance it would be inappropriate for the crew to disclose the DNACPR information to the patient.
    - parents or legal guardians of children or young people for whom a CYPADM form has been completed will always know this, as this form is intended to be parent held.

      It is important to note that the absence of particular details on the form ***must***

not *delay the transport of any patient.*

5. although SAS staff should always ask for a DNACPR/CYPADM form if it is indicated that resuscitation should not be attempted, it is not necessary that one is seen. A verbal confirmation by a senior clinician responsible for the patient (this can include a senior nurse) is sufficient evidence as long as it is clear to all that this clinician is taking responsibility for the decision. This should always be documented by SAS staff on the e-prf or PTS record as appropriate. Where possible the clinician should be requested to follow this up with written confirmation at the earliest opportunity. Copies of DNACPR forms are not appropriate and should not be requested.

It is not the responsibility or duty of SAS staff to determine or question the validity of any DNACPR form or CYPADM order. If a senior clinician instructs that such an order exists, then this must be acted upon and communicated. Any such form only requires to be signed to be valid, and SAS staff need only know the resuscitation status and details of destination should the patient die en-route*.*

Patient Examination

If a patient with a DNACPR/CYPADM order is being transported and appears to die, the crew should stop the vehicle, at the first available, safe location and carry out an examination:

Response: speak to the patient to ascertain response. Pinch the earlobe if no verbal response. If there is a response, commence oxygen therapy.

Airway: if there may be foreign objects involved (eg the patient has been eating or gag-reflex has been weak) open the airway using head-tilt/ chin lift or re-positioning. Otherwise, move on to Breathing.

Breathing: Check for breathing using chest movement and audible checks. If the patient is breathing, commence oxygen therapy.

Circulation: check carotid and radial pulses. If there is a pulse, manage the patient as per JRCALC 2013 Guidelines for unconscious patients.

If the patient is pulse-less, and family are present, actions should be dictated by the emotional state of those present. Usually, a simple statement *('I'm sorry, he/she has died'*) should be sufficient. If not, the actions listed below should be taken. PTS crews should immediately inform ACC, and request support from Ambulance Clinicians qualified to confirm the fact of death.

Management

Immediately a qualified ambulance clinician has confirmed that the patient has died ACC should be notified and the contact number on the form should be communicated to them. If this is a PTS crew, the patient is travelling alone and a destination is stated on the DNACPR /CYPADM form, the crew should take the patient to that destination. The chosen location should be a healthcare facility, to allow for verification/ formal certification. Special circumstances would need to exist for SAS staff to deliver a body to a private dwelling (such as the presence at the dwelling of a clinician),. If the stated destination is the patient's home the PTS crew should consider whether they have the equipment to deliver the body to the home

and if not they should request ACC to dispatch an A/E crew to do this (if not already on scene). SAS should not normally be requested to take a body to a private address.

If the patient was travelling with other patients, ACC should dispatch an operational crew to the scene. The operational crew should remove the body to the facility designated on the DNACPR/CYPADM form or, by agreement with the clinician noted on the form, to an appropriate mortuary. If the body is to be taken to a mortuary the EMDC should liaise with the clinician to ensure the mortuary is prepared to accept the body and arrange for death certification. Every effort should be made to remove the other patients from the vehicle to an appropriate place whilst awaiting the operational crew, or at least screening the body away from the view of the other patients. The safety of the remaining patients is paramount.

If ambulance clinicians are aware that a DNACPR/CYPADM order exists but the family in attendance is requesting that cardiopulmonary resuscitation is attempted, they may use their discretion over what actions to take - but should take the earliest opportunity to explain to the family that CPR would not be/has not been successful and that transfer of the body to an acute hospital is not appropriate. In such circumstances, attempted resuscitation would be a last resort where the ambulance clinicians feel it is the right thing to do for that particular patient and their family, taking their needs at the time of bereavement into consideration.

If a DNACPR/CYPADM form is present and the Ambulance Clinician is prepared to verify / declare that death has taken place, then provided there are no suspicious circumstances the police do not need to be called to attend. The Out of Hours (OOH) medical and/or Community Nursing Service, however, should be called to attend to support the family and provide guidance about after-death care.

Children have the same rights as adults in these circumstances: a valid DNACPR/CYPADM order must be in place and observed unless a senior clinician has instructed that one is in existence. There are separate policies on resuscitation for children and adults in Scotland, and these should both be consulted.

If the patient with a DNACPR/CYPADM form is being transported home the form may be left in the home in the envelope for the GP or community nurse or placed at the front of the community nursing folder if present. The ambulance crew must have already ascertained that the family and patient are aware of the DNACPR form as above.

This policy has taken into consideration equality and diversity issues and those with vulnerabilities - on occasion this may require further specialist guidance or some flexibility in applying the plan in full.

None of the above affects the application of current Recognition of Life Extinct / Declaration of Death procedures.

If there is any doubt about the existence or validity of a DNACPR/CYPADM order and a patient appears to die, resuscitation must be carried out using the appropriate resuscitation guidelines unless the crew are certain that CPR is not in the patients wider benefit, for example where a patient is in the final stages of a terminal illness.

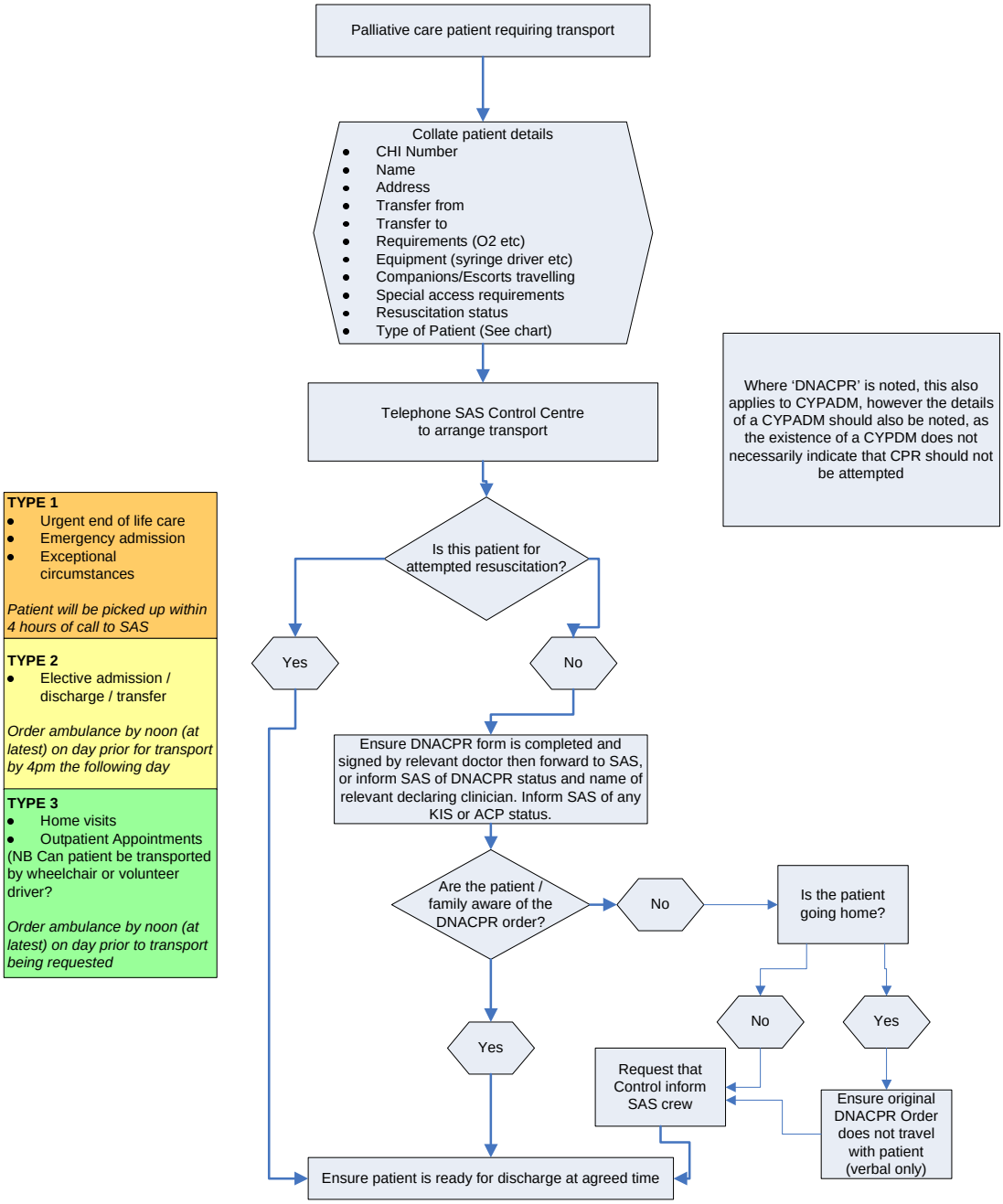
First Responders and Emergency Responders

Currently, the training given to First Responders does not provide them with the necessary background to make decisions over DNACPR/CYPADM status. First Responders should presume in favour of resuscitation until support arrives. This position is likely to change as training and legal advice is updated. First Responders should not be sent to incidents when it is known that a DNACPR orders exists for the patient, or to any expected death. If it is clear that an expected death has taken place, the actions taken should generally rely on advice from ACC or OOH clinicians, and be dependent on the expectations of the bereaved family.

Specific groups/teams of Emergency Responders may be permitted to apply DNACPR/CYPADM policies on a case-by-case basis: if a particular group has received approved and appropriate training, and has been given specific permission to do so by the Medical Director. This specific permission will not be taken to apply to other SAS groups of staff.

HEALTH CARE PROFESSIONALS

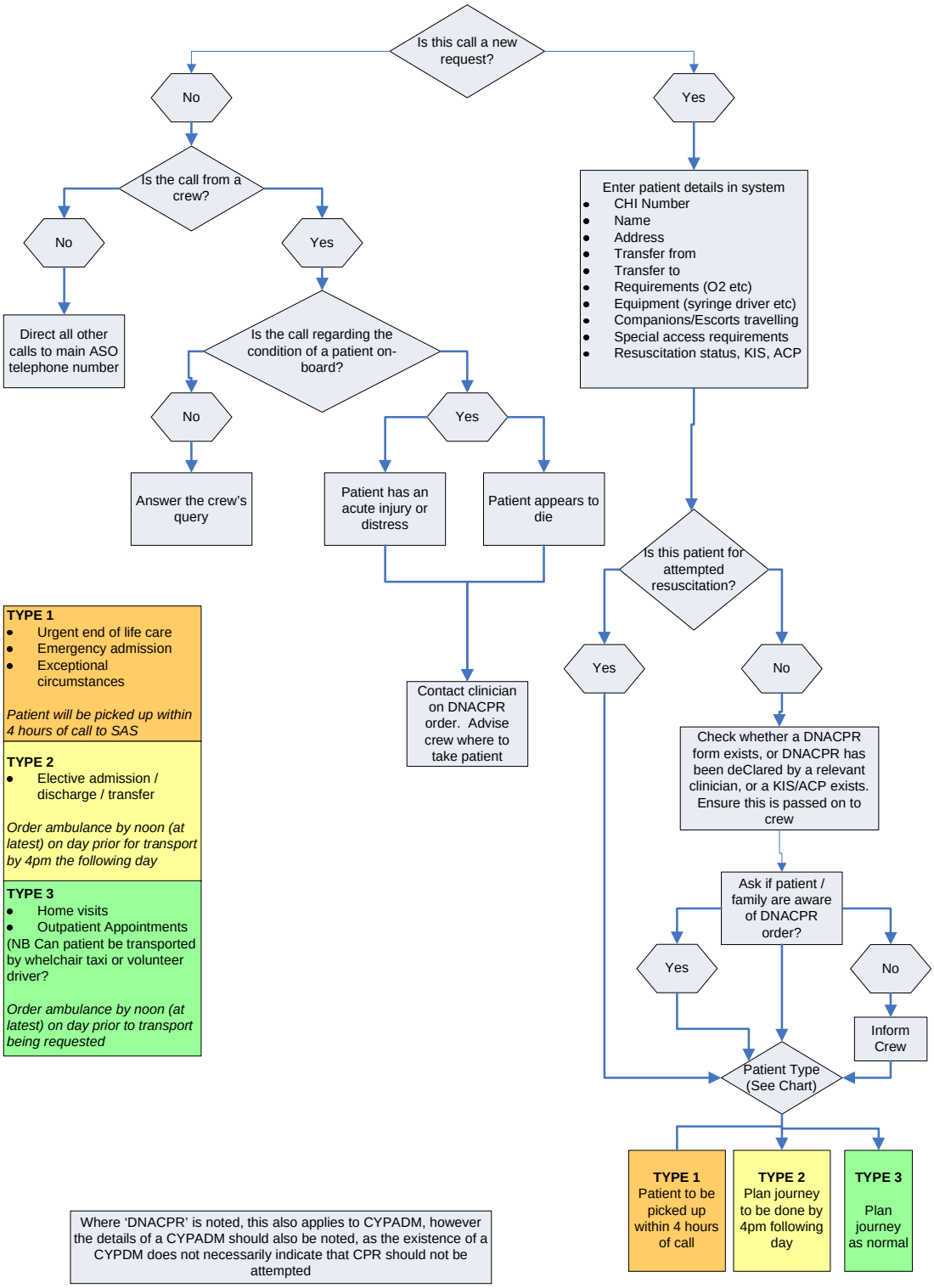
How to book transport for palliative patients



ALL SCOTTISH AMBULANCE SERVICE CREWS ARE TRAINED IN THE SAFE TRANSPORT OF SYRINGE DRIVERS, OXYGEN AND COMFORT MEASURES

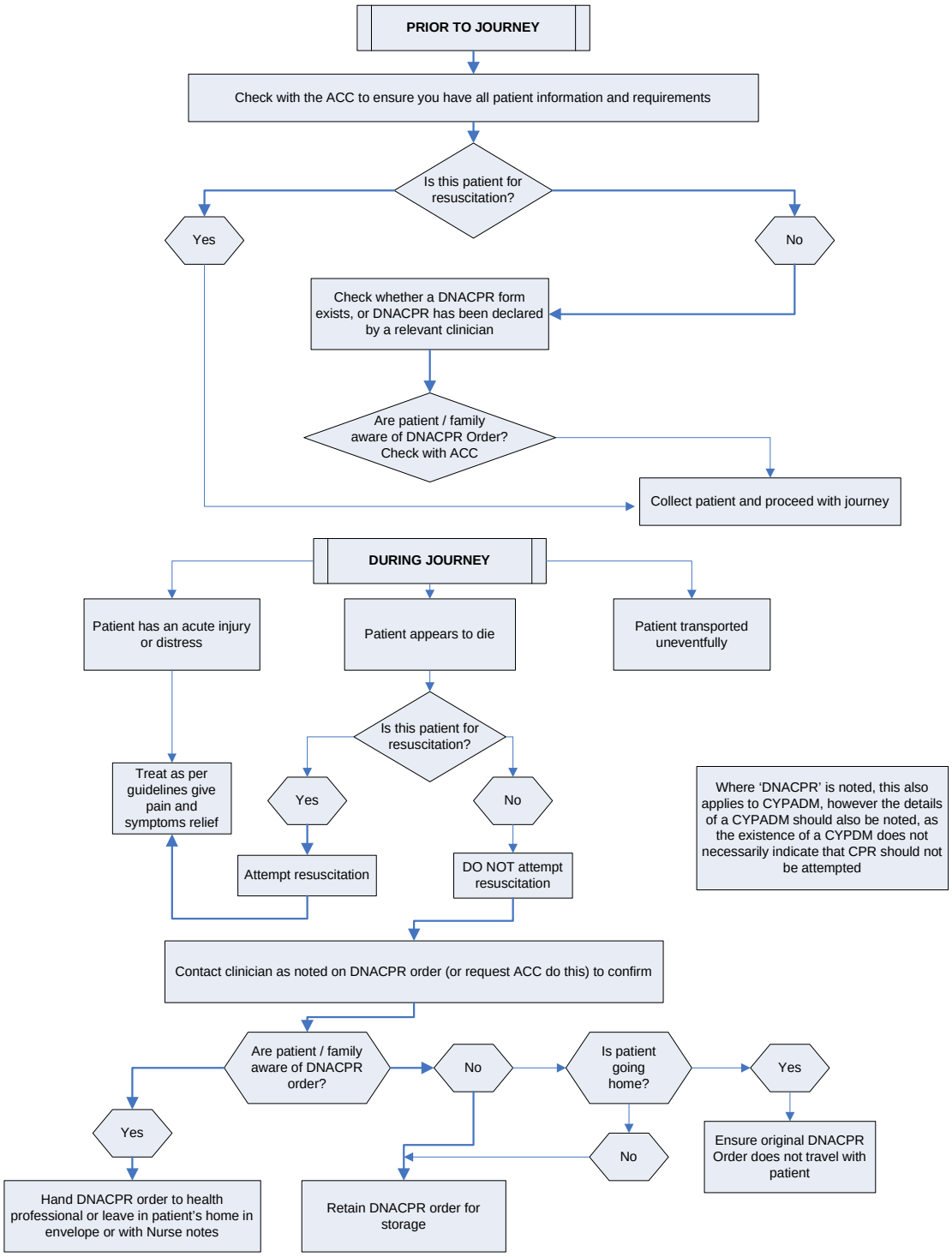
AMBULANCE CONTROL CENTRE STAFF

How to deal with transport requests for palliative patients



VEHICLE CREW STAFF

Transport arrangements for palliative patients



Section 7: References

BRITISH MEDICAL ASSOCIATION, (2007). *Decisions Relating to Cardiopulmonary Resuscitation, a joint statement from the British Medical Association, Resuscitation Council (UK) and Royal College of Nursing*. London: BMA.

Scottish Ambulance Service Consent Policy 2012

AACE/JRCALC Patient Confidentiality Guideline 2013

AACE/JRCALC Recognition of Life Extinct Guideline 2013

NHS Scotland DNACPR Policy

NHS Scotland Resuscitation Planning Policy for Children and Young Adults

Scottish Ambulance Service Children's Policy

Scottish Ambulance Service Clinical Care Standard No 1: Generic and Courtesy Care

Scottish Ambulance Service Consent Policy

Scottish Ambulance Service Declaration of Death Policy

Scottish Ambulance Service Vulnerable Persons Strategy

Scottish Government Health Department: Living and Dying Well 2008, 2010

Scottish Government Health Department: Interim Guidance – Caring for People in the Last Days and Hours of Life 2013

NHS Scotland: What to do after someone has died – information for you

Section 8: Acknowledgements

Scottish Partnership for Palliative Care:

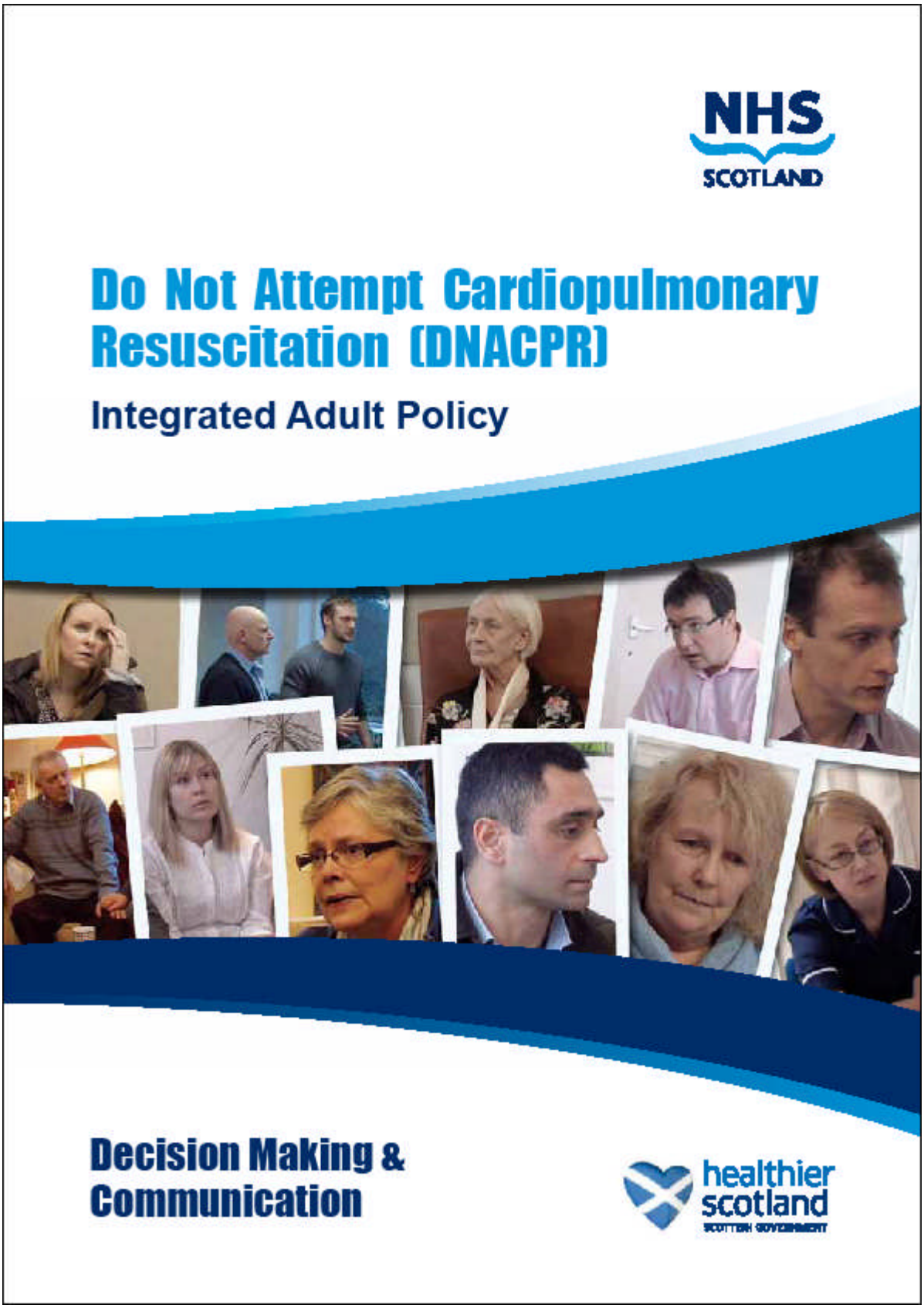
Consultation:

Dr Pat Carragher, Medical Director, Children's Hospice Association Scotland
Margaret Colquhoun, Senior Nurse Lecturer, St Columba's Hospice, Edinburgh
Dr Jane Edgecombe, Consultant in Palliative Medicine, NHS Greater Glasgow and Clyde
Shirley Fife, Nurse Consultant Cancer & Palliative Care, NHS Lothian
Jackie Husband, Director of Clinical Services, Prince and Princess of Wales Hospice
Dr Alistair McKeown, Palliative Care Consultant, Prince and Princess of Wales Hospice
Dr Juliet Spiller, Consultant in Palliative Medicine, Marie Curie Hospice, Edinburgh
Elizabeth Thomas, Director of Clinical Services, St Margaret of Scotland Hospice

Consultation organised and collated by Pauline H. Britton, Publications & Group Liaison Officer, SPPC.

Appendix 1 - NHS Scotland DNACPR Form

(Please click on the page below and it will open to the full document)



Appendix 2 - CYPADM Form

Full Name: .....

Date of Birth/CHI Number: .....

Address: .....

..... Postcode: .....

GP Name & Address: .....

Telephone no: ..... Postcode: .....

NHS SCOTLAND

CHILDREN/YOUNG PEOPLE ACUTE DETERIORATION MANAGEMENT (CYPADM)

This **CYPADM** form ***must*** be used for children/young people before their 16th birthday
This **CYPADM** form ***could*** be used for selected young people after their 16th birthday.

This Individualised Plan is for use in ALL AREAS

Home, Hospitals, Emergency Departments, Schools, Ambulance Services, Hospices, Respite Care Facilities

Children/Young People must continue to be assessed, managed and receive treatments that are appropriate for their health and comfort irrespective of their Resuscitation status. A more detailed Anticipatory Care Plan may also be in place for some Children/Young people

In the event of a sudden collapse or deterioration, the following measures would be appropriate to consider where clinically indicated

(Clinician completing form must tick actions agreed and score out the actions not required)
Senior clinician/carer attending should decide whether to call Resuscitation back up (2222 in hospital or 999 out of hospital)

- ☐ Attempt full resuscitation
- ☐ Mouth to Mouth/ bag & mask ventilation
- ☐ Suction upper/oral airway/tracheostomy tube
- ☐ Administer O_2 until looks comfortable
- ☐ Comfort and support to the child and family

Additional information:

Responsible Consultant (mandatory):.....

SIGNATURE (mandatory):.....Bleep..... DATE:.....

THIS MANAGEMENT PLAN HAS BEEN FULLY DISCUSSED AND AGREED WITH

Name:..... Relationship:.....

CO-SIGNATURES:(optional)

1. PATIENT/PARENT/WITNESS SIGNATURE:..... DATE:.....
2. PATIENT/PARENT/WITNESS SIGNATURE:..... DATE:.....

Review Date for CYPADM		Responsible Clinician	

THIS FORM SHOULD BE REVIEWED AS CLINICALLY INDICATED or AT LEAST YEARLY
A new form should be completed after review and old one cancelled

Appendix 3 - Further Guidance
Palliative and End of Life Care
Introduction

Few, if any, health care workers would claim to be able to imagine what it feels like to be in the palliative care phase of a life-threatening illness. Some may feel that their professional or life experience enables them to put themselves, to some extent, in the place of a family member or friend in these circumstances. However, each individual patient, family member and friend will respond to this challenging experience in their own unique way. If we wish to understand and display empathy then we need to listen, not only to what the patient and family may say, but also to the feelings they express.

In addition it may be useful to consider what has been written about palliative care and what research findings show that could inform practice. This is a huge topic, but the focus here is on:

- What is meant by the palliative care approach?
- How can health care workers help patients and families remain hopeful?
- How can families be supported at the time of death?
- How can staff care for themselves and be supportive of colleagues?

The Palliative Care Approach

Palliative care has been described as an approach that focuses on quality of life for patients and families facing the problems associated with life-threatening illness [(1)]. Part of this is end of life care, i.e. the care required by people as they approach the end of their lives [(2)].To provide palliative or end of life care requires all staff to look at the patient and family as a whole and to work towards relief of pain and other symptoms, while also providing psychological, social and spiritual support [(3)]. Team working plays a vital part if sound and compassionate care is to be achieved at the end of life. The Scottish Government action plan [(4)] clearly states that all health care staff should be able to deliver this kind of holistic care to the patients and families that they come across in the course of their work. The action plan also emphasises that patients with any far advanced, progressive and life-threatening illness need this sort of approach.

Fostering hopefulness

One of the surprising things that research has shown over the past twenty years is that patients and families can remain hopeful right up to the end of life in certain circumstances[(5)]. If the patient's physical comfort is maintained, if caring relationships are demonstrated and if the patient and family feel valued as individuals, then hope may be fostered [(3,5)]. Similarly enabling the patient and family to retain an element of choice and control has been found to be helpful. These are all integral to the role of all health care staff, but it is perhaps useful to be reminded of their positive effect on how patients, family and friends feel. The presence, or indeed absence, of these may profoundly influence the rest of the patient journey and, for families, may have an impact on into bereavement.

Supporting families

As noted at the beginning, individual patients and families will respond differently to different situations [6]. For most patients and families, the palliative care and end of life phase of illness is one of many losses [7, 8] – for example, for patients it may be the loss of health, loss of job, loss of role and indeed loss of a future. By the time they are reaching the end of life, the patient and family may have travelled a long journey with illness. That needs to be kept in mind if staff are to understand patient and family emotions and behaviour. Some people cope or adjust to illness by confronting it, while others avoid thinking about it. Some express their emotions, while others actively try to seek information and address issues [8]. In particular it is important, when supporting family members around or at the time of death, to remember that they may experience and express a whole range of complex emotions,[9] such as shock, anger, sadness, disbelief, or perhaps even relief. No assumptions can be made. It is also important to balance the need to be present and supportive without being intrusive.

Caring for yourself and colleagues

Being with and caring for patients and families at the end of life can be stressful and emotionally exhausting. It may raise issues for staff about the fragility of their own lives and of the lives of those they love. It may remind them of personal experiences of illness and death in the past. It is, therefore, very important that individual staff members care for themselves and are thoughtful in relation to their colleagues. There are lots of books and articles about staff stress and caring for staff. There are things that organisations can do [10, 11] e.g. hold reflective meetings, offer confidential staff counselling services. There are, however, also things that individuals can do [11, 12], such as maintaining a healthy work-life balance, talking things through with a colleague or manager, listening to colleagues when it becomes clear they have had a difficult shift.

Conclusion

Finally then, in caring for people at the end of life, it is important to treat each patient and family as individuals, who will have travelled a unique journey with illness. All health care staff have a role in providing the holistic care involved in the palliative care approach. By addressing pain, respecting the patient and family as individuals and demonstrating good interpersonal skills, staff may foster a real sense of hopefulness even at the end of life, as may giving patients and families control through choice, wherever possible. Support for the family at and around the time of death needs to be offered, but without being intrusive. Team working and excellent communication are also central to this approach. *The End of Life Care Plan* developed by The Scottish Ambulance / Scottish Partnership for Palliative Care provides a framework for all these elements of care to be integrated into everyday practice.

(M. Colquhoun. April 2014)

References and further reading

1. World Health Organization. 2004. *Definition of Palliative Care*. Available at: http://www.who.int/cancer/palliative/definition/en/

2. Faull, C. 2012. The Context and Principles of Palliative Care. In: Faull, C., de Caestecker, S., Nicholson, A., Black, F. eds. *Handbook of Palliative Care.* Chichester: Wiley Blackwell

3. Colquhoun, M. and Hill, V. 2011. Sustaining Hope in People with Cancer. In: Fawcett, J.N., McQueen, A. eds. *Perspectives on Cancer Care*. Chichester: Wiley Blackwell

4. Scottish Government. 2008. Living and Dying Well: A National Action Plan for Palliative and End of Life Care in Scotland. Available at: http://www.scotland.gov.uk/Resource/Doc/239823/0066155.pdf

5. McIntyre, R., Chaplin, J. 2007. Facilitating Hope in Palliative Care. In: Kinghorn, S., Gaines, S. eds. *Palliative Nursing: Improving End of Life Care.* Edinburgh: Bailliere Tindall

6. Proot, C., Yorke, M. 2013. *Life to be Lived.* Oxford: Oxford

7. Mitchell, G., Murray, J., Hynson, J. 2008. Understanding the Whole Person: Life Limiting Disease across the Life Cycle. In: Mitchell, G. ed. *Palliative Care: A Patient Centred Approach.* Abingdon: Radcliffe.

8. Faull, C. and Taplin, S. 2012. Adapting to Death, Dying and Bereavement. In: Faull, C., de Caestecker, S., Nicholson, A., Black, F. eds. *Handbook of Palliative Care*. Chichester: Wiley Blackwell

9. Becker, R. 2010. *Fundamental Aspects of Palliative Care Nursing*. London: Quay Books

10. Jamieson, L., Teasdale, E., Richardson, A., Ramirez, A. 2010. The Stress of the Professional Care Givers. In: Hanks, G., Cherny, N.I., Christakis, N.A., Fallon, M., Kaasa, S., Portenoy, R.K. eds. *Oxford Textbook of Palliative Medicine*. Oxford: Oxford University Press.

11. Setch, F. 2007. Looking after Yourself In: Kinghorn, S., Gaines, S. eds. *Palliative Nursing: Improving End of Life Care*. Edinburgh: Bailliere Tindall.

12. Pettifer, A. 2013. Resolving my own Feelings after a Patient has Died. In: De Souza, J., Pettifer, A. eds. *End of Life Nursing Care.* London: Sage

Robin Lawrenson
Clinical Performance Manager
Scottish Ambulance Service
rlawrenson@nhs.net