Focus on anticipatory prescribing for end of life care

GPC guidance, updated March 2018

Introduction

The Dying without Dignity (2015)[1] report highlights that end of life care could be improved for 350,000 people a year in England alone and that poor communication, planning, pain management and co-ordination lead to tragic and avoidable cases of needless suffering. In this context, and following the demise of the Liverpool Care Pathway, the Scottish Palliative Care Guidelines (2016)[2] have been updated and NICE published their Care of Dying Adults Guideline NG31[3] in December 2015.

Providing a good death at home is a vital part of modern general practice, but presents unique problems for the primary care team, especially during the out-of-hours period when access to the patient's own general practice and regular pharmacy may not be possible.

Anticipatory prescribing is designed to enable prompt symptom relief at whatever time the patient develops distressing symptoms, and is based on the premise that although each patient is an individual with individual needs many acute events during the palliative period can be predicted and management measures put in place in advance. Palliative care is traditionally thought of as being a part of cancer care, but many life-limiting illnesses such as cardiac, neurological and respiratory diseases can benefit from this approach.

Although the benefits of anticipatory prescribing are well recognised, some GPs have concerns about prescribing in this way, and this guidance is designed to help GPs with their prescribing in this important field.

This document is not intended to be used as clinical guidance, but to clarify the issues around anticipatory prescribing and end of life care. For ethical guidance and BMA views on making end-of-life care decisions, please click here.

Anticipatory prescribing: 'Just in Case' boxes

Anticipatory prescribing is designed to ensure that there is a supply of drugs in the patient's home, combined with the apparatus needed to administer them, with the intention that they are available to an attending clinician for use after an appropriate clinical assessment. Once prescribed these drugs belong to the patient and have the same legal status as other prescribed controlled drugs.

In certain situations, it might be appropriate for drugs to be prescribed with the intention that they are to be administered by a patient's family, although in such cases clear instructions are required; an example might be the provision of rectal diazepam for a patient at risk of convulsions. These supplies are normally provided in a specially marked container, commonly called a 'Just in Case' box.

[1] www.ombudsman.org.uk/sites/default/files/Dying_without_dignity.pdf
[2] www.palliativecareguidelines.scot.nhs.uk/
[3] www.nice.org.uk/guidance/ng31

GPs are not the only health professionals able to provide the 'Just in Case' medications. Nurse Prescribers, particularly those specialising in palliative care, can also provide them, but many GPs find that the time of supplying these medications is a good opportunity to discuss with the patient and family their hopes and fears about the coming weeks. An example of a drugs administration document used for Just in Case boxes is available in **Appendix 1**.

Difficult issues with 'Just in Case' boxes

There have been a number of concerns raised about anticipatory prescribing

1) **Drugs remaining in the community for extended periods of time:** Many, if not most, anticipatory drugs will not be required. Consequently, these drugs may end up discarded in the community with very little supervision of their use or disposal.

2) **Prescribing for the future:** Normal good medical practice has the provision of a prescription as one of the last elements of the consultation, following and not preceding clinical assessment. Anticipatory prescribing inevitably involves uncertainty and risk concerning the drug's correct use, and prescribers are properly wary of providing drugs with less control over their use than is normal.

3) **Inappropriate administration:** Doctors who prescribe drugs in this way have very little control over what will happen when the drug is actually administered, and some have expressed concerns about their responsibilities should such a drug be administered inappropriately. There has been a concern that the availability of such drugs might encourage their administration without proper assessment (for example midazolam supplied for terminal restlessness might be authorised for administration over the phone when a visit and examination might have revealed a distended bladder as the cause of the patient's distress).

Guidance for best practice

1) The health professional authorising administration of a pre-supplied anticipatory drug must accept responsibility for that decision. The availability of such medication in the patient's home is in no way a substitute for proper clinical evaluation at the time of a change in the patient's condition.

2) The list of usual anticipatory drugs supplied should be agreed locally, with input from the Local Medical Committee (LMC), other lead GPs, and specialist palliative care professionals such as the local hospice and Macmillan Teams. Blanket prescribing of the same medications for all patients is discouraged; the contents of the 'Just in Case' box should be based on the individual patients underlying condition e.g. the choice of anti-emetic depends on the cause of any nausea and vomiting; the choice of opiate may be altered depending on prior pain relief.

3) The normal starting doses should be agreed and available on a pre-printed sheet to minimise the chance of prescribing error.

4) Quantities supplied needs to be balanced between adequate supply and waste. For example, as a minimum, sufficient quantities should be provided for a patient over a bank holiday weekend.

5) 'Just in Case' boxes should contain as a minimum the anticipated drugs, administration equipment, written instructions as to dose and indications, and a means for recording administration.

6) The prescriber needs to be satisfied that the patient and carers understand the reasons for the provision of the medications at that time. This is a good time to explore with the patient and family the prognosis, and to ensure they understand how to access care appropriately in the event of deterioration in the patient's health (also see 'DNACPR' section below).

7) The Out of Hours service, and all others involved in the care of the patient, must be made aware of the clinical situation and of the availability of drugs.

Maintaining hydration at the end of life

Maintaining hydration at the end of life is a controversial and emotive subject. The most recent palliative care guidelines [NICE NG31][3]) acknowledge the evidence base for medically assisted hydration is unclear but ***some patients may benefit***.

If it is thought someone may be suffering from symptoms of dehydration such as thirst, agitation or delirium then the doctor needs to carefully consider whether or not assisted hydration may help. A trial of hydration should be considered to see if this helps symptom control. This may be using a NG or PEG tube if already in place, or if not, then by subcutaneous drip infusion which can be delivered in the community. Re-assess after 12 hours and only continue if there is a clinical benefit.

Clear conversations with the patient and family about the need to re-assess frequently, and their expectations of any possible improvement should be undertaken.

The BMA ethics department is working with the Royal College of Physicians and the GMC to develop new guidance on clinically assisted nutrition and hydration and adults who lack the capacity to consent, some of which will be relevant to GPs.

Do Not Attempt Resuscitation (DNACPR)

Whilst discussing the prognosis with the patient and family, it may also be appropriate to have discussions about decisions regarding cardiopulmonary resuscitation. The health care professional should establish the communication needs and expectations of the patient, taking into account if they would like a person important to them to be present and involved. It is difficult to decide when is the most appropriate moment to discuss this sensitive matter, but in general patients and their relatives appreciate involvement at an earlier rather than later. Explain uncertainty but avoid false optimism. Explore whether they have an advance statement or stated preferences about their care, their views on allowing natural death and decisions about cardiopulmonary resuscitation.

The GMC advises in their *Treatment and care towards the end of life* guidance that:

'You must make it clear to the healthcare team and, if appropriate, the patient and those close to the patient that a DNACPR decision applies only to CPR. It does not imply that other treatments will be withdrawn or withheld.[4]'

[4] www.gmc-uk.org/guidance/ethical_guidance/end_of_life_after_a_DNACPR_decision.asp

There is currently no nationally available DNACPR form, although the Resuscitation Council (UK) provides a template[5] and there is a unified form available in Scotland[6].

In some areas, the *Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)* form may be available. The ReSPECT form is much broader that a DNACPR form, and records recommendations to guide immediate decision-making about a person's care and treatment in a future emergency situation where they lack capacity. This includes a recommendation as to whether CPR should be attempted or not. Further information is available at **www.respectprocess.org.uk**.

The BMA has published joint guidance with the Resuscitation Council and Royal College of Nursing, ***Decisions relating to cardiopulmonary resuscitation***, most recently updated in 2016 to add greater emphasis on ensuring high-quality timely communication, decision-making and recording in relation to decisions about CPR.

Further reading

BMA Ethical guidance on making *End-of-life decisions*

BMA joint guidance *Decisions relating to cardiopulmonary resuscitation*

GMC guidance on *Treatment and care towards the end of life*

NICE *Care of Dying Adults Guideline* 2015 www.nice.org.uk/guidance/ng31

***Dying without Dignity* report, England 2015**
www.ombudsman.org.uk/news-and-blog/news/too-many-people-dying-without-dignity-ombudsman-service-report-finds

Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)
www.respectprocess.org.uk/

Scottish Palliative Care Guidelines www.palliativecareguidelines.scot.nhs.uk

Gold Standards Framework (GSF) www.goldstandardsframework.org.uk

The GSF guidance is designed to provide a "systemic evidence based approach to optimising the care for patients nearing the end of life delivered by generalist providers". Useful guidance can also be found in GSF's Examples of good practice resource guide.

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[5] www.resus.org.uk/pages/DNARrstd.htm
[6] www.scotland.gov.uk/Publications/2010/05/24095633/15

Appendix 1 - Example of a drugs administration document used for 'Just in Case' boxes

RECORD OF CONTROLLED DRUG AND ADDITIONAL DRUGS ADMINISTERED

PATIENT NAME _____ **NHS NUMBER** _____
PATIENT DOB _____ **GP NAME** _____

DRUGS ARE TO BE GIVEN ACCORDING TO SYMPTOMS.
THIS SHEET MUST BE SIGNED AND DATED BY A DOCTOR/NURSE INDEPENDENT PRESCRIBER

SUBCUTANEOUSLY VIA SYRINGE DRIVER OVER 24 HOURS							**AS REQUIRED (PRN) DOSE**				
Symptom	Drug	Possible range over 24 hours	Actual dose	Prescriber's signature (and print name)	Date		Drug	Possible range	Actual dose and frequency	Prescriber's signature (and print name)	Date
Agitation/terminal restlessness	Midazolam	Initially 10mg					Midazolam	2.5mg-5mg (if frail 2.5mg) S/C			
Nausea & vomiting or agitation	Haloperidol	Initially 5mg					Haloperidol	1mg S/C			
Excess chest secretions	Hyoscine Butylbromide	Initially 60mg					Hyoscine Butylbromide	20 mg S/C			
Pain relief	Diamorphine Hydrochloride	If opiate naïve 10mg					Diamorphine Hydrochloride	If opiate naïve 2.5mg			

Date	Time	Drug	Expiry date	Batch no:	Dose	Site	New stock	Prior stock	Stock balance	Destroyed Wasted Discont	Signature