

*‘One day I will find the right words, and they will be simple’— Rethinking DNACPR at a national level*

Article

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**‘One day I will find the right words, and they will be simple’<sup>1</sup> – *Rethinking DNACPR at a national level***

Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) notices remain controversial. After all, they are telling a patient or her family that she is dying and cannot be saved. The clinical grounds for adopting a DNACPR are centred upon either the futility of such intervention, or that the disadvantages heavily outweigh any possible benefits so that it is not in the patient’s best interests.<sup>2</sup> Equally, a competent patient may also request a DNACPR; the rationality, reasonableness or wisdom of which cannot be disputed by the clinician.<sup>3</sup> But discussing DNACPR notices is not easy and practices vary between regions, and between institutions. Over the last decade, a number of different Trusts have initiated reviews to encourage better communication and documentation of DNACPR. Yet, empirical studies reveal:

‘evidence of variation and suboptimal practice in relation to DNACPR across health-care settings, reduced quality of care for patients with DNACPR orders and inappropriate expectations of the outcome of CPR among family members and the general public.’<sup>4</sup>

Most damning of all,

‘Health-care professionals do not discuss DNACPR with patients and their families and they do not communicate adequately with each other about a patient’s DNACPR status. Doctors either avoid discussing with patients/making the decision or do not see this as a priority. There is a lack of knowledge about process and confusion over documentation within and between health-care organisations.’<sup>5</sup>

Further, inappropriate use of CPR due to confused procedures and lack of initial discussion has been documented and identified as a cause of patient suffering.<sup>6</sup> A two-fold need is thus apparent: (i) better management of patient understanding and expectation; and (ii) coherent, standard process for initiating and documenting treatment discussions. The Resuscitation Council (UK) has recently made recommendations in order to deal with some of the difficulties identified above, yet their proposals remain advisory.<sup>7</sup> This discussion reviews current practices and suggests that the time has come for a national standardised approach in England and Wales<sup>8</sup> to the process of initiating and documenting DNACPR, along with a dedicated programme to increase public understanding of what is involved. Importantly, such an approach would both ensure that the respective legal rights and obligations of patients and professionals are respected, and provide clear public health gains. At the very least, a national conversation can help achieve common understandings and expectations, which will go some way towards ensuring that the patient remains at the heart of the decision-making process.

## **Context of DNACPR**

Most complaints to the Parliament and Health Services Ombudsman concern end-of-life care and treatment in hospital, and over half of these raise poor communication as the reason for concern:

‘Communication failings appear at all levels; between clinicians and patients; between clinicians and family; within clinical teams; and finally, between the hospital and care in the community.[...] What is clear ... is that healthcare professionals are not always having the open and honest conversations that are necessary in order for carers and

family members to understand both the severity of the situation and also the choices that will need to be made.’<sup>9</sup>

It is not therefore a surprise that the Health Select Committee, Fifth Report *End-of-Life Care* (2015) recommended review of DNACPR in acute hospital settings and consideration in the context of an overall treatment plan.

### **Current practices**

A systematic review published in 2015 identified the variety of nomenclature, forms and procedural guidelines set at a local level.<sup>10</sup> For example, out of those sampled, the terms ‘DNACPR’, ‘DNAR’, ‘not for CPR’ or ‘AND’ (Allow Natural Death) were used. There is also much diversity on whether there is any review period set for the forms, who should complete and sign them, the duration of the validity of each decision, and on the portability of the document. For some areas, the document ‘travels’ with the patient and includes access for ambulance and community staff, but this varies between Trusts.<sup>11</sup>

What is clear from the systematic review and other empirical research carried out to date,<sup>12</sup> is that there is an unease amongst medical professionals about the uncertainty: (i) as to the right time at which this judgment should be made; and (ii) as to the reaction of the patient and/or family to the idea of not attempting resuscitation. The difficulty is exacerbated by a lack of understanding amongst the general public of what CPR actually involves (often informed by hyperbolic media reports about unwieldy use of DNACPR notices and glamourised representations of successful CPR bringing someone ‘back to life’) and the fear that a DNACPR actually goes beyond simple resuscitation and may lead to a reduction in the overall level of care.<sup>13</sup>

A number of Trusts have adopted revised forms and practice in the use of DNACPR. The ‘Deciding Right’ programme adopted in the North East was identified as best practice<sup>14</sup> and involves a distinct DNACPR form which allows for detailed documentation of the reasons behind the decision. In Devon, ‘Treatment Escalation Plans’ were pioneered and have been adopted in some other Trusts with the aim of being introduced at an earlier stage providing the opportunity for discussion on a variety of treatment options.<sup>15</sup> The Universal Form of Treatment Options has been piloted in Cambridge (and was referred to in the *Tracey* case discussed below) and includes wider treatment options as well as DNACPR. The most recent proposals from the Resuscitation Council (UK) aim to offer a unified, consistent approach to end-of-life treatment decisions and are seen as a step towards ‘changing the culture of resuscitation decision-making’.<sup>16</sup> Nevertheless, I would argue that in order to make real progress, a mandated national programme would be beneficial.

### **Towards a national approach?**

The question of the need for the Secretary of State to impose a national standardised national framework policy for the use of DNACPR orders was raised in the much publicised case of Janet Tracey<sup>17</sup> concerning the imposition of a DNACPR notice without consulting either the patient or her family. In this case, the claimants suggested that the Secretary of State should be under such a duty. However, the Court of Appeal held that the duty imposed upon the Secretary of State was discharged by the commendation of the professional Joint Statement<sup>18</sup> coupled with the use of a Health Service Circular on Resuscitation Policy which included reference to the legal duties on Trusts to ensure that patients (and where relevant families or carers) are involved in the process.<sup>19</sup> However, the Court did find that:

‘consistency on important matters of policy (rather than minor matters) is desirable. If there are inconsistencies (or indeed any other deficiencies) in the involvement of patients in DNACPR decisions, they need to be resolved’.<sup>20</sup>

I have already identified that there are discrepancies in practice and an overall desire to improve how and when such decisions are made. The current work of the Resuscitation Council (UK) is clearly grappling with this, but a standardised national approach would have a number of advantages for both medical professionals and the public.

(i) Public engagement and education:

A national strategy gives the opportunity for public engagement and education. Ultimately, it is this which is at the heart of a successful DNACPR policy because it allows for improved communication and understanding between professionals and the public. This has been evidenced in other jurisdictions where greater investment in education has been found to be key in improving both understanding and use of DNACPR notices. For example, in Australia, a Government initiative has increased education of overall advance care planning as studies there had shown that the lack of a standardised national programme was part of the difficulty in ensuring consistent, coherent and appropriate decision-making, especially concerning end-of-life issues.<sup>21</sup> In the UK, the *Dying Matters* Coalition has gone some way to supporting better public discussion of dying and bereavement,<sup>22</sup> but its focus is rather on the dying process and death. Thus, there remains a need for a certain level of myth-busting with respect to what CPR is for and what it can do. Public debate would thus allow clarity to be brought to what is involved and encourage the adoption of simple, consistent terminology. It would enable clearer understanding of the clinical realities of CPR and provide assurance that such notices relate only to CPR and not overall care at end-of-life. Most importantly, it would contribute to respecting the legal obligations concerning DNACPR. As the *Tracey* case highlighted, there is a presumption in law of the involvement of the patient in the decision-making process and part of the procedural obligations on healthcare Trusts requires that decision-making policies are clear, accessible and available to the public. A national public awareness campaign coupled with national information leaflets could ensure this and provide consistent information across all regions and all health care settings. British Columbia in Canada has adopted a high profile campaign to increase public understanding of advance care planning and CPR decisions. A leaflet explaining ‘Medical Orders for Scope of Treatment’ (MOST) encourages relevant discussion with clinicians (‘early and often’) about the treatment options available.<sup>23</sup> Such patient education could be a useful element in ensuring patient involvement and understanding on this side of the Atlantic.

(ii) Professional development

Greater public engagement would also be of benefit to practitioners as the studies to date reveal that even for professionals, the DNACPR may sometimes dictate an overall care plan, when in fact it should only be an element within it.<sup>24</sup> There could be clearer guidance as to when it is appropriate to instigate discussion relating to CPR: if it seen as part of the overall care plan, it would be easier to engage with it an earlier opportunity, perhaps while a patient is still able to communicate her wishes and opinions. This would ensure better respect for an individual’s rights and facilitate the assessment of each patient’s best interests, as required by law. The *Tracey* judgment makes clear that an individual’s right to a private life, protected under article 8 of the European Convention on Human Rights, imposes an obligation for patients to be involved in the decision-making process where that decision relates to an intimate aspect of their life. Further, the *Mental Capacity Act* 2005 expressly requires a doctor to consider the patient’s best interests, which include her ‘wishes and feelings’... ‘beliefs and values’.<sup>25</sup> The Government’s response to the Review of Choice in

End-of-Life Care<sup>26</sup> in 2016 confirmed pilot projects which will explore new ways to support clinicians to initiate meaningful conversations with patients.<sup>27</sup> By emphasising that such discussions are an essential part of *clinical* intervention may go some way to ensuring that these conversations take place, and with appropriately qualified and trained staff.<sup>28</sup> Further consideration needs to be given to the timing of such discussions and the normalisation of raising CPR within the context of overall care for certain patients.<sup>29</sup> Clearly for some patients, CPR will not fall to be considered. For others, it will be helpful to include CPR in the treatment plan and to bear in mind that ultimately, the decision concerning CPR is one made at the time it is needed by the health professional who is present. Having a clearly documented DNACPR notice as to the reasons for the decision, whilst not binding, clearly assists the professional to act in that patient's best interests.

An additional advantage of a national structure is that it could facilitate consideration of Advance Directives or Lasting Power of Attorney (LPA). Evidence suggest some confusion for practitioners as to the differences between these mechanisms and how they fit in with DNACPR orders.<sup>30</sup> It would also publicise these legal mechanisms to encourage greater uptake. The Health Select Committee Report expressly notes limited recourse to LPA and recommended that the cost of such should be reviewed and reduced.<sup>31</sup> It is clear that as we live longer and are likely to suffer more co-morbidities which eventually render us incapable of making decisions, more of us may wish to draw up either advance directives or appoint someone to speak for us should we become incompetent.

Just like an advance directive or LPA, the DNACPR as part of the overall care plan should be a portable document, available at all points of care delivery providing consistency for healthcare workers in different sectors (acute, community, ambulance, nursing home etc..). It would also mean that where practitioners move from one trust to another, there would be no need for further training to convert to an alternative format.

### (iii) Public health benefits?

There are likely public health benefits from a robust, standardised national plan which places early discussion of CPR at the forefront insofar as it is to be expected that incidences of inappropriate CPR would be reduced. Although it has been found that even where a DNACPR notice has been in a patient's notes, CPR has nevertheless been carried out (and, not surprisingly, most often with unsuccessful outcome)<sup>32</sup> it is to be hoped that where patients and families are realistically informed and involved in the decision about CPR, clinicians will be more comfortable in respecting that decision. At present, the common discomfort or unwillingness of clinicians to discuss CPR, coupled with lack of knowledge or understanding of the procedure for the patient, mean that any DNACPR notice is not treated with sufficient respect. The NCEPOD Report 2012 noted a number of interventions despite the existence of a DNACPR decision. It follows that if less (inappropriate and unsuccessful) CPR is undertaken, there will be a knock-on benefit in terms of diminishing on-going futile treatment, and potentially admission to ICU, which may be occasioned if CPR is attempted where it should not be.

What is central to ensuring respect for both professional and legal obligations is that the use of DNACPR or any other treatment decisions are not tick-box exercises, and that each clinician feels supported in taking the time to conduct the necessary discussions. The duty to consult and involve a patient and her family in the decision-making process involves a discussion, and one which should be seen as a crucial element in a patient's care.<sup>33</sup> This discussion should be undertaken at the earliest stage where the patient's wishes and feelings

can be aired and taken into account, wherever possible. The process must also allow for any decisions taken to be reviewed if the situation changes. The conversation must be clinician-led, but patient-centred. As William Osler revealed over a century ago, ‘It is much more important to know what sort of a patient has a disease than what sort of a disease a patient has’.

In terms of DNACPR, neither the difficulty of the discussion, nor the mis-placed expectations of the public, justify excluding the patient or her family from the decision-making process. The sooner we open a national conversation on this, the sooner we will be able to ensure that dignity of each and every patient is respected and that we are all using the same, simple words to mean the same things.

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<sup>1</sup> From the Beat Generation novelist, Jack Kerouac: *The Dharma Bums* (1959) Penguin Modern Classics (Reprinted 2000).

<sup>2</sup> See for example, Cardiopulmonary Resuscitation – standards for clinical practice and training, joint Statement from the Royal College of Anaesthetists, The Royal College of Physicians, the Intensive Care Society and the Resuscitation Council (UK); Decisions relating to cardiopulmonary resuscitation, A joint Statement from the British Medical Association, the Resuscitation Council (UK) and The Royal College of Nursing (2016); Treatment and Care toward the End-of-life: Good Practice in Decision Making, General Medical Council Guidance, available at: [http://www.gmc-uk.org/guidance/ethical\\_guidance/end\\_of\\_life\\_care.asp](http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp).

<sup>3</sup> It is an established legal principle that a competent person may refuse medical treatment for any reason whatsoever: *Re T* (Adult: refusal of medical treatment) [1992] 4 All ER 649.

<sup>4</sup> Perkins GD, Griffiths F, Slowther A-M, George R, Fritz Z, Satherley P, *et al.* Do-not-attempt-cardiopulmonary-resuscitation decisions: an evidence synthesis. *Health Serv Deliv Res* 2016;4(11)

<sup>5</sup> *Ibid*, Chapter 3, page 38.

<sup>6</sup> *Time to Intervene? A review of patients who underwent cardiopulmonary resuscitation as a result of an in-hospital cardiorespiratory arrest*, National Confidential Enquiry into Patient Outcome and Death (NCEPOD) Report 2012. Available at: [http://www.ncepod.org.uk/2012report1/downloads/CAP\\_fullreport.pdf](http://www.ncepod.org.uk/2012report1/downloads/CAP_fullreport.pdf).

<sup>7</sup> *Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)*: <https://www.resus.org.uk/consultations/respect/>.

<sup>8</sup> As health is a devolved issue, NHS Scotland has adopted a national policy and framework for the documentation of DNACPR notices, which was updated in September 2016: <http://www.gov.scot/Topics/Health/Quality-Improvement-Performance/peolc/DNACPR>.

<sup>9</sup> *End-of-Life Care*, Fifth Report 2014-15, Health Select Committee, HC 805, March 2015, at para 58.

<sup>10</sup> Perkins GD, Griffiths F, Slowther A-M, George R, Fritz Z, Satherley P, *et al.* Do-not-attempt-cardiopulmonary-resuscitation decisions: an evidence synthesis. *Health Serv Deliv Res* 2016;4(11), Chapter 4.

<sup>11</sup> M.Clements, J.Fuld, Z.Fritz, Documentation of resuscitation decision-making: a survey of practice in the UK (2014) 85(5) *Resuscitation* 606.

<sup>12</sup> As well as the Perkins *et al* study (above note X) see also, Z.Fritz, J.Fuld, Development of the Universal Form of Treatment Options (UFTO) as an alternative to DNACPR orders: a cross-disciplinary approach (2015) 21 *Journal of Evaluation in Clinical Practice* 109.

<sup>13</sup> The Health Select Committee Fifth Report (above note X) refers to evidence that the perception that overall care is reduced when a DNACPR is in place may be shown to be a reality. This was part of the downfall of the Liverpool Care Pathway, now abandoned as its implementation was unsatisfactory to address end-of-life care, contrary to the original intention behind it: see *More Care, Less Pathway, A Review of the Liverpool Care Pathway*, 2013, available at: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/212450/Liverpool\\_Care\\_Pathway.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf).

<sup>14</sup> <http://www.nescn.nhs.uk/common-themes/deciding-right/>

<sup>15</sup> Review of DNACPR and development of Treatment Escalation Plans has been undertaken in Wiltshire and Wessex.

<sup>16</sup> Z.Fritz, A.Slowther, G.D.Perkins, Resuscitation policy should focus on the patient, not the decision (2017) *British Medical Journal* 356:j813.

<sup>17</sup> *R (Tracey) v Cambridge University NHS Found Trust* [2015] QB 543 (CA).

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<sup>18</sup> *Decisions Relating to CPR: Joint Guidance* BMA, Resuscitation Council UK and RCN, 3rd edition, 1<sup>st</sup> revision 2016.

<sup>19</sup> Per Longmore LJ in *Tracey* (above) paras 74-87.

<sup>20</sup> *Tracey* (above) per Master of the Rolls at para 86.

<sup>21</sup> I.A.Scott, G.K.Mitcell, E.J.Reymond, M.P.Daly, Difficult but necessary conversations – the case for ACP (2013) *Medical Journal of Australia* 199 (10):662-666.

<sup>22</sup> *Dying Matters Coalition* set up in 2009 to raise awareness about dying, death and bereavement:

<http://www.dyingmatters.org/>.

<sup>23</sup> *Medical Orders for Scope of Treatment*, Interior Health, Canada, available at:

<https://www.interiorhealth.ca/YourCare/PalliativeCare/ToughDecisions/Documents/MOST%20Brochure.pdf>. Other Canadian and American States have adopted similar approaches, developed from Physician Orders for Life-Sustaining Treatment instigated in Oregon in the early 1990s.

<sup>24</sup> The NCEPOD Report, *Time to Intervene?* (above note X) recorded that patients with DNACPR notices were often not given other active treatment or relevant tests, which would have been given to someone in a similar condition without a DNACPR notice, at p.65.

<sup>25</sup> Section 4 (6) (a) and (b) Mental Capacity Act 2005.

<sup>26</sup> *What's important to me: Review of Choice in End-of-Life Care*, Independent Review, February 2015 available at:

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/407244/CHOICE\\_REVIEW\\_FIN\\_AL\\_for\\_web.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/407244/CHOICE_REVIEW_FIN_AL_for_web.pdf).

<sup>27</sup> In response to a Parliamentary Question, David.Mowat, MP confirmed that these pilots in Southend and Airedale should be completed by Summer 2017: Parliamentary Written Question 58816, House of Commons, answered 16<sup>th</sup> January 2017.

<sup>28</sup> *National Commitment on End-of-Life Care: Government Response to the Review of Choice in End-of-Life Care*, Department of Health, July 2016, available at:

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/536326/choice-response.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/536326/choice-response.pdf).

<sup>29</sup> A small study piloted the use of DNACPR discussion for all hospital admissions. However, not surprisingly, it was felt that this was not appropriate and a disproportionate burden on staff: Treatment Escalation Plans – a tool to aid end-of-life decision-making? P.Paes and C. O'Neill, *BMJ Supportive and Palliative Care* 2012;2.

<sup>30</sup> Evidence submitted to the Health Select Committee Fifth Report, volume 11, Evidence Q225.

<sup>31</sup> An earlier report by the House of Lords found poor uptake of LPA: *Select Committee Report on the Mental Capacity Act 2005—Post-legislative scrutiny* (2014) HL Paper 139.,

<sup>32</sup> *Time to Intervene?* NCEPOD Report 2012 (above note X).

<sup>33</sup> The NCEPOD Report *Time to Intervene?* (above note X) found that in over 86% of the cases reviewed, there was no evidence in the patients' notes that their CPR status had been discussed.