Dying is the most grown-up thing we ever do – so let's take it seriously

In his third Reith Lecture, 'the problem of hubris', Boston surgeon Atul Gawande lamented what he saw as the over-medicalising of patients in their last days. He suggested that doctors should ask patients their goals, their fears, and the kind of trade offs they are prepared to make between these, so that they can work together to help those last moments be as meaningful and enjoyable as possible. However, '*doctors*', he suggested '*…. can deny people these moments, relegating them to the care of strangers alone in an intensive care unit,' and he said 'the way we can forget this out of obtuseness and neglect, is I think cause for our shame'.*

The response of some doctors was to sympathise with his aims but protest at his charge of *obtuseness*. Here is one example, from a particularly candid and thoughtful clinician, that I want to return to later.

But obtuseness is an interesting word, and I wonder whether, before we deny it, we could fruitfully explore it. If we look in a dictionary we find that it means ***'the quality of being slow to understand'*** and that its origins are in the 16th century from the Latin *obtusus* meaning ***dulled***, the past participle of *obtundere* '***to beat down'.***

I want to suggest that in relation to dying we have all become dulled. We have all been beaten down into not taking it seriously enough, and that in doing so we have not only made it difficult to die well, but we have made it less easy to live well. Without a constant acceptance of the fact that we will not always be alive it is difficult to treasure our lives as the wonder that they are. So we will all benefit from an active and generous acknowledgement of our own death that is the opposite of today's squeamishness and avoidance.

I want to revisit, too, the meanings of other words that have become dulled – especially those of 'care' and 'comfort' – and suggest that unless we can be confident of both of these towards the end of our lives we will not find it in ourselves to think generously and helpfully about dying.

I'm also going to wonder how heath care professionals can overcome their instincts to prevent us from taking dying seriously.

This feels to me to me vitally important and I have chosen to explore and write about it because the current conversations on death and care of the dying (whether very local or more national) seem to me to be either cowardly or alienating or proprietorial, or all three! I characterise them to myself as a kind of irrelevant hybrid of Enid Blyton and Pollyanna. The language used seems so very far away from my own experiences, feelings and needs as a daughter of a very frail parent in her last years, as someone who has had breast cancer and knows it can recur at any time, and as a friend and colleague of several wonderful clinicians.

So I have written this partly for myself, and partly for interested clinicians and service managers, in the hope that it may influence the shape of services and the nature of care. Having worked with both groups for many years I know how committed most are to offering a good service, and also the day-to-day pressures you experience. I hope you will find here thoughtful, heartfelt reflections of an informed and independent thinker, questioning, not criticising, and illuminating not insisting.

Part One: Have we become dulled to the fact that we will die?

Living longer, flourishing less

In 1816 John Keats was 21, he had just finished studying medicine at Guy's hospital and been awarded his license to practice as an apothecary, physician, and surgeon. He chose instead to become a poet.

At that time 20% of Londoners died of consumption, as Keats' mother had done, life was precarious and precious and Keats is reported to have asked to be given 10 years before he died, to be able to write the poetry he knew he had within him.

A little less than 200 years later few 21 year olds would dream of asking for 10 years. Now that we have clean water, clean air, work that is less physically arduous and dangerous, safer housing, antibiotics and antiseptics, we expect not only our three score years and ten, but twenty or thirty. Now complaints of age discrimination are made if the uptake for chemotherapy is lower in 85 year olds than other age groups.

This increase in longevity in a relatively short time is frankly amazing. So it is not surprising if we have not yet developed ways of responding to this that are in our best interests. Instead, with our assumption of 70 years or more we are profligate with our moments.

Now that we no longer confront death on a daily basis we can so easily distract ourselves for decades from any thought of dying, and be taken by surprise and resentment, even outrage, when confronted with it. We appear to share with many other animals a natural and proper mourning and grief on bereavement, but many now have so little experience or expectation of sadness, loss and mourning that they seek (or are offered) medical help for it. Somehow we have lost our awareness that, as the Taoist saying went, life is made of ten thousand joys and ten thousand sorrows.

We seem to have forgotten that life is a process, even a project, of learning how to live, of learning how to flourish. And that this project continues right to the inevitable end, when we learn how to live and flourish while dying. I suggest it is important we recover an acknowledgment of death and dying, and perhaps more generally of the ten thousand sorrows, and that in doing so we will be able to flourish in ways our consumer society (with its insistent promise of delivering the ten thousand joys) fails to deliver.

In previous eras many religions have encouraged the contemplation of death. People who have engaged in this attest that, although initially distasteful, even frightening, we can soon see it as not only natural but also valuable, essential for the wellbeing of our children and future generations. We can see it as generous as well as sad, necessary as well as frightening, lonely but also an experience we share with all other living beings. More than that, we learn to relish our experience of being alive, not in fear of losing it, but in wonder at its preciousness. It allows us to recognise the danger of life becoming merely an exercise in distraction and dissatisfaction.

Without this we have what Tim Dartington describes as the 'adolescentisation of society': 'Society has become acculturated to what we may recognise as adolescent behaviour'.

It is, he suggests, characterised by desperate but temporary attachments, fierce competitiveness, preoccupation with status, and self absorbed people confusing high ideals and selfish acts. In an adolescentised society morality is built on fairness, but fairness in which one aims to get more and more in order to have ones fair share. Another feature of this adolescentisation is a belief in technological progress as the solution to all ills.

Tim Dartington's wife, Anna, died of Alzheimer's disease in her early '60s. One chapter of his very valuable book is her reflections. She says 'You could certainly say I've grown up. Before I was busy being clever and planning to do things……… I have had to learn to be patient and to just let myself be'. This, she points out, 'is difficult enough without having to be cheerful all the time'. She also distinguishes among those involved in her care between 'busybodies and mediators', the latter 'work with me to negotiate the new reality'.

It was this that made me wonder if we could describe dying as the most grown up thing we ever do, and whether the mismatch between this and the adolescentisation of society accounts for our failure to prepare ourselves and flourish as we do so. Also whether failure to recognise/realise this (the grown up ness needed) is the greatest difference between busy bodies and mediators. And whether a lot of professional education is about training us to be busybodies?!

Is our fear of dying preventing us from living, from flourishing?

When John Keats asked to be given ten years before he died, it was to be able to write the poetry he knew he had within him. As it happens he was given 5, and died tormented at not having written the work he was meant to, but having made the fullest use possible of those five.

More recently Stephen Sutton reminded us that knowing of imminent death can focus us on making the very most of being alive. Gordon Aikman too.

Perhaps, as so many who have really contemplated their death have observed, it is not dying we should be afraid of, but not living. It seems that without an active acknowledgement of our own death we cannot maintain a sense of the preciousness of life, able to revel in the wonder of it, treasure it and not waste it. We lose a sense of really living our lives, of taking an interest in them from the inside, not of filling in a cv for others to judge, but of doing and being for our own sake, much more sensitive to what is happening for us from moment to moment, *living* the ten thousand joys and sorrows rather than making them a backdrop to whatever short-lived aim is pre-occupying us. In short, we lose our ability to fully flourish.

In that case then, discussions that include an acknowledgement of death will help us to flourish, to live our lives to the full, and we should not avoid them. And since we consult health care professionals (HCPs) when worried about our health, perhaps we should actively encourage them to take opportunities to help us with this acknowledgement. Instead of allowing us to brush away our fears, our HCPs could gently challenge us to give them due regard and even befriend them.

We cannot leave this responsibility to them, it is our own, but if high status professionals we meet at times of stress collude with us in ignoring our death it is difficult for us to remember that. Perhaps we need as a society to give them that permission, helping them to see that by doing so they are not diminishing our lives but helping us to flourish.

Part Two: Have we dulled the process of dying?

Taking dying seriously

I suggest that if we were confident in the care we would receive in the last months and days of life we would find it easier to actively acknowledge that we will die and be more able to live our lives to the full. Can we have that confidence? What would we look for in such care?

Elsewhere I have derived a definition of care as '***acts of work and courage that enable flourishing***' and this is often a useful checklist: did I, did we focus on their flourishing? work hard enough? act courageously enough? Anna Dartington's distinction between mediators and busybodies is played out here: mediators focus on the *flourishing* of the other, busybodies on *fixing* them.

At this time too care will almost certainly require us to offer comfort, a word that derives from the Latin and originally meant '***to be strong/brave together***' (It was only in the 16th century that it acquired a sense of 'ease').

This original meaning feels to me appropriate for the care at this life stage, when we recognise that dying is natural and essential and at the same time sad and frightening. Comforting, understood like this, would involve not falsely reassuring, not running away from difficult things, but indeed (in deed) being courageous together. Again, mediators will try to offer genuine comfort, recognising the courage needed by the patient, and busybodies will be tempted to offer trite reassurance.

Where can dying be taken seriously?

More than half of deaths in the UK are in hospitals.

So, if we want these to be 'good deaths', we need to be sure that they are offering this kind of care and comfort, and in a mediator spirit. Is that what they do?

Dartington is again instructive here. With his background in psychoanalysis and open systems theory, he suggests that every organisation has a primary task – the task which, if not fulfilled, would mean the organisation ceased to be what it thinks it is; and that activities that are not primary are undertaken effectively only if exceptional energy is deployed.

Is supporting the dying the primary task of hospitals? Clearly not. Are they deploying exceptional energy to support people who are dying? What would 'exceptional energy' look like? Perhaps that the people involved most closely with dying patients would be senior practitioners skilled enough to judge the resources required and ensure they are available. This may be the case, for a few deaths, those supported by a strong palliative care team. Otherwise isn't it often delegated to the most junior and most harassed who have little experience or success in negotiating the resources they need?

If this is the case, then we are not putting exceptional energy into this task of supporting people in their last days, and we place major requirements for energy and maturity on the patients themselves.

Perhaps this isn't inappropriate. If we all knew what to expect from hospital care at this time, then other individuals and organisations with energy and maturity to spare could provide support. But it needs us all, and especially those leading hospitals, to openly acknowledge this and find ways of putting (and welcoming) it into practice. Hospitals may argue they do not need this, but then they would need to convince us that their clinicians take dying seriously and do not see it as something to be avoided at all costs. This would require such a major shift in the underlying beliefs of all those involved, that we are more likely to be successful if we seek other alternatives.

What about social and community care?

Traditionally social care was often very much better than was health care at helping people live with loss and frailty. So, until recently, this may have been a better organisational home for care at the end of life. But social care has changed. It, too, is now dominated by an agenda of rehabilitation rather than support.

Often this focus on rehabilitation is undertaken to avoid encouraging dependency, indeed dependency has become rather a dirty word. And of course there are unhealthy forms: where people's ability to flourish is stunted because they fail to challenge themselves appropriately.

But dependency is also a natural part of life. We all pass through a period of dependency at the beginning of our lives, many of us will become dependent again for a while at their ending, and some of us will have phases in our lives where we experience transitions from one state to another where we need support until we have adjusted to our new reality. We could describe this as healthy dependency: natural, proper, and inevitable. If we deny people who are healthily dependent the help they truly need, we cause suffering rather than benefit. Dartington gives an example of an exhausted, very frail, very elderly lady being observed and instructed in how to wash dishes. Her decades of washing up should now have been behind her and the care she needed was to have it done for her.

'What we are seeing' says Dartington 'is that the most vulnerable [here he means appropriately dependent] members of society have to live with the anxieties of those much more powerful than themselves'.

More worrying still: 'In a culture of fighting back, of heroic effort against misfortune, the patient who does not get better may provoke feelings of aggression and sadism, accompanied by anxiety, guilt, depression and reparative wishes'. This is no longer a setting where good care for those who need it can safely be expected.

So neither hospitals nor social care are good 'homes' for care for people who are dying. What about NHS community services? Again, they were once a good home for such care but the steady drift of NHS funding from low tech, low status community care to high tech, high status hospital care has left these underfunded, under-skilled, and over stretched to the point of desperation.

Thus the prospects as I have just described them, for people who are dying, are looking bleak. In practice they are bleaker still.

Services under pressure

All these services feel under pressure and fearful of being overwhelmed by demand. They, therefore, put in place triage systems that limit access to the most needy. John Seddon repeatedly demonstrates that measures restricting access to those 'who really need it' typically amplify demand by at least five times. This 'failure demand' occurs because people have needs that have not been met, for which they seek support time and again, meeting ever more stringent entry criteria – due to the 'rise in demand' caused by their initial knock back. Seddon demonstrates that when resource allocators hold their nerve, identify and treat what the patient needs, the cost savings are huge. This is so counterintuitive his voice is often not heeded.

So: fearful services, anxieties of the powerful, dying not a primary task …., these are all contributing to a situation where typically between 1/4 and 1/2 of our lifetime call on NHS resources is in the last 6 months of our lives; where a very large proportion of that resource is spent on trying to deny us access to care from a range of different services; and where, often, a person's last six months of life is characterised by a care experience that offers little comfort, little reassurance, allows them to think they don't matter, can leave them feeling frightened and unwanted. At the same time the same fearful and unwelcoming system automatically, reflexly, puts great efforts in to keeping them

alive if they show any signs of dying: blue light ambulances; A and E; Emergency hospital admissions. A fraction of this would surely pay for all the help they needed to enjoy and even flourish in their last six months.

That we know this happens surely demonstrates the extent to which we have become dulled, obtuse.

Are these the only possibilities?

But we have not yet considered the care on offer from family members, friends, and local communities (such as clubs or churches). Care often involves as many – or more – of these as paid professionals. Currently however these two groups are poorly integrated and have two different agendas.

Paid carers, funded by NHS and Local Government, aim to *meet* the needs of their patients/clients. They assess those needs, devise a care plan, and aim to implement it.

Friends and family *respond* to the needs of their friend or relative – adjusting the nature and timing of their visits and other support accordingly. Inevitably they sometimes they find the schedule of these paid-carer visits helpful and reassuring, and sometimes they find them restrictive, burdensome or unnecessary. If the definition of care is 'acts of work and courage that enable flourishing' then merely meeting predefined needs is *not* care, it may be a part of it but not the whole.

Could we, instead of the current expensive and inhumane approach to the last months of life, move towards a system that does enable flourishing? What might this look like?

A system in which paid carers could respond to needs as they change would allow resources to be used less wastefully and more valuably. This would also happen if paid and unpaid carers complemented each other. Is such an arrangement possible?

It would require those involved to have some autonomy and flexibility, to be able to some extent to manage their own time, increasing and decreasing input as clients needs required, and doing so in ways that made the best use of not only their time but that of others. In our daily lives we do this all the time, so it is not an extraordinary ask.

However we immediately run up against the problem that organisational managers are required to command and control, and economise and account, so we need to try to find ways of bringing together informal resources with the state provision that do not expose NHS managers and their organisations to censure. How could we do that? What might such a system look like?

The Buurtzorg model in the Netherlands perhaps provides a good example.

Suppose (as Tim Dartington imagines in his book) a small number of patients, their informal families and other carers, together with their paid carers from health and social care, formed a self-managing unit. There could be agreed care plans but framed as responses to needs as they arose. More specialist resources, such as palliative and dementia care, would support a number of such teams. Could this offer the flexibility, continuity, and consistency, responsiveness and comfort that is needed?

Such a self-managing community is not a panacea. With different personalities in an emotionally charged area there will be inevitable tensions. But it also has the potential to offer care that is responsive to needs as they arise, in a way it is difficult to imagine otherwise. And a community of this kind may be more able to develop confidence in managing symptoms and deciding not to call an ambulance than can isolated families or care homes.

This mix of professionals with family members and friends could also yield another benefit. It should reduce the degree to which ‘end of life’ care professionals claim this as their territory and presume to speak for patients. Well-intentioned, knowledgeable, thoughtful, concerned – palliative care teams are all of these things. But perhaps we could reflect again on how we can draw on the undoubted expertise of these specialists without handing over to them the overall responsibility for managing the dying process. Could we draw on their expertise in in palliating physical symptoms, and in being acquainted with the physical and psychological processes of dying, and then ask them to step back and let the patient decide what kind of a role they want these specialists to fulfil, before they take on an expert advocacy role with the rest of the system to help make this happen? Could we ask more of them still: that they take on a role in encouraging us to acknowledge and think about our dying, while we are in the middle of life?

Part Three: Un-dulling the last days: helping everyone involved to flourish

As Anna Dartington observed, carers tend to fall into two categories -the busybodies and the mediators -and perhaps we all have both tendencies. The busybodies among us (and the busybody elements in us all) will want to brush away the sorrows and solve our problems for us, and in doing so 'fix' us or our situation. Mediators, instead, work with us to help us negotiate our new reality. They offer us their strength, their courage, to help us approach a situation we fear – and so comfort (are courageous with) us.

In this section I draw on two sets of experiences, my own of engaging closely with my mother in her last months and those described in the blog I introduced in the opening paragraphs. I am doing so, not to suggest in any way that these kinds of experience are universal or even common, but to reflect on specific aspects of what a mediation approach can offer.

My own experiences

About a year before my mother died I received a letter, as her carer. I binned it; I didn't see myself as a carer but as a daughter. Nor did I see myself as having needs of my own, even though I was beset with life changes. In the previous three years my father had died, I had discovered breast cancer and been through the gruelling mill of surgery and chemotherapy, divorced, and lost my closest work colleague to mesothelioma. Through it all I maintained a busy and highly committed professional life. Now my mother was over 90, had had heart failure for many years that was becoming increasingly difficult to control, was very frail and vulnerable, and less and less able to enjoy life. I moved my office into her house and was physically present for a part of every day. I thought I was caring well – managing well. I saw myself as frenetically busy, yet loving and generous with my mother, against a backdrop for both of us of grief, loss and change.

I can still think that, but I also see how, in that busy-ness, as we drew increasingly upon medical and nursing services to an almost dominating extent, we became so caught up in a set of care transactions that we failed to look at the bigger picture. We missed the opportunity for something else. I failed to support her emotionally through the most difficult thing she would ever do, and to grow in my own ability to face that as I did so. I think I saw it as an interruption to my life rather than an essential part of it.

In reflecting on what that letter could have said, that would have spoken to me where I was at that time, I wonder what kind of support could have woken me up to what I was failing to see – before it was too late. What could have woken us both up (undulled us both), and helped us to negotiate our new realities?

I think perhaps what we needed then was some help in becoming more skilful in our mediator impulses, and that it could have taken the form of a discussion of the following points.

Point one: conflicting emotions

It is natural to feel conflicted when caring for and about someone you love who is moving towards the end of their life, with all the uncertainty and unknowability surrounding that. It is natural to want to love and support them while at the same time sometimes resenting the need to do so, and itching to be free of that responsibility, especially when it is unclear whether this period will last weeks, months or years. As much as I loved my mother I also loved my work. Although I saw her everyday there was always something important to rush off to, and those little errands that she minded so much about weren't at the top of my to-do list.

I see now that we didn't share with each other what mattered to us. We weren't open with each other about how we were feeling. Hearing from a sympathetic third party that these tensions are natural, even vital, would have enabled us to explore together how we could support each other in what was important to us. It wouldn't have eliminated pressure points but would have allowed empathy to sit alongside irritation and disappointment. Perhaps we could have done this ourselves, without facilitation, if we had had a template. Without either I think we veered between feeling everything was OK and everything was not OK. So we were never in the right space with the right kind of energy to introduce this conversation.

Much later I discovered guidance from websites such as Dying Matters but wouldn't have found them helpful – I see them as assuming that everyone involved is whole heartedly altruistic and cares only about the other not about themselves or their other objectives in life. I would have found this actively chastising, alienating and unhelpful.

Point two: 'inside-out' strategies for pain, breathlessness and fear

One of the big advantages of the palliative care team becoming involved was that we could now talk openly about dying. The team members themselves were thoughtful, and helpful, and their very involvement was reassuring to us both. Mother was relieved to know that pain control in the form of oral morphine would be available to her at home – and was, later that same day. Her great fear however was of drowning, which we had heard was a common manner of death in heart failure patients. (She longed to go with a heart attack but knew this was highly unlikely.) There appeared to be little help that could be offered for that, and as I look back on it now, I see that the help available was all 'outside-in' help.

I can't recall any help with 'inside-out' approaches: strategies my mother could adopt herself as she neared the end. Some aspects of mindfulness for example: learning how to take an interest in emotions such as fear, and in physical symptoms such as pain, rather than getting overwhelmed by them. Developing a practice of focusing attention and thus helping her mind not to run riot, not to jump from one thought to another to an alarming other. Learning how to meditate on, and rest in, love, compassion, acceptance, and joy. Learning how to contemplate her death constructively so that her fear could sit alongside a sense of naturalness, ubiquitousness, generosity and love.

When my mother experienced hallucinations with the morphine and chose not to take it I realised that someone who appears to be peacefully dozing can be experiencing all sorts of highly emotional and perhaps distressing brain states not apparent to those with them. I began to wonder whether the palliation is of more benefit to relatives and carers than to the patient. This feels to me to be another reason for a greater focus on 'inside-out' strategies for dealing with pain, breathlessness and fear.

Point three: emotionally resourcing ourselves

As a family we had always eaten healthily and knew the value of daily exercise. Those were habits that served us well in these difficult last months, but we had never really considered how we might keep ourselves fit emotionally.

In my rather frenetic search for serenity (!) after my own surgery and chemotherapy I came across teachings in secular Buddhism that I was finding helpful. I'd also kept abreast of lessons arising from modern neuroscience and from evolutionary psychology. But it wasn't until afterwards that I came across resources that allowed me to pull these together into a coherent approach that was nourishing for me. I continue to find this valuable, and am just sad that we didn't have it available to us while mother was alive, when they would have helped us both – individually and together. My experience of working with clinicians suggest to me that HCPs could benefit from this themselves, and in doing so feel able to assist their patients in this direction.

Point four: not leaving it to health care professionals to introduce the subject of dying

I only realised afterwards that almost every professional involved will avoid starting a conversation with you about your death and how you want to die. They can collude with you in pretending it isn't going to happen. They think they are being sensitive, but in doing so they are keeping us from approaching it with courage, they are depriving us of comfort in that they are not offering us their strength so that we can be strong together. So if we want to be able to prepare for our death and make the very most of our life until then we will probably need to raise the topic ourselves. The more direct we can be, the more we demonstrate our genuine desire to think about it, the more we can express our fears, then the more courageous we allow them to be, and the greater clarity and comfort they can offer. The more, too, we can help them to develop these skills, so this will also be a generous act on our part.

An important part of such a discussion should be about CPR. Despite its very low success rate and the, often severe, damage caused by these resuscitation efforts it is (ridiculously, scandalously, amazingly) standard procedure unless one has explicitly and formally opted out. There are now calls for this opt-out to be termed Allow Natural Death (as opposed to Do Not Attempt Resuscitation) and to make such resuscitation opt in rather than opt out. But it isn't yet.

So the importance of having this conversation needs to be widely known, along with the importance of keeping its record, the lilac form, on display at all times including, crucially, taking it into hospital if admitted, and making sure that ward staff (including those coming on duty later) know about it.

Why do I make this point so vehemently? Because despite my mother's frailty, history and being on an End-of-Life pathway, when she had a heart attack (the heart attack she had so wanted) in the early hours of the morning while awaiting an operation for a fractured neck of femur, resuscitation was apparently attempted for 45 minutes.

Point five: helping hospitals help us (instead of vice versa)

As we've already seen, the primary task of a hospital is to offer a short episode of clinical care in an otherwise healthy phase of life, and in that context the agenda is rightly set by the clinical team.

But here, where the hospital episode is a small, transient episode in a much longer care trajectory, the focus needs to be different. The information flows almost need to be inverted with the role of hospital staff that of enabling patient and carers to care at home.

This is where an intervention from a palliative care team is extremely helpful – in preventing any escalation of clinical care. So keeping them informed of any unplanned admission is vital.

Point six: Trying to make hospital and hospice stays more endurable

To hospital staff wards are busy, busy places and convivial too. To patients they can be interminably boring and lonely. For people whose sight and hearing are failing this is especially so. I never did find ways around this and, until hospital wards and especially hospital beds are redesigned, can only suggest it is helpful to know what to expect. For generations who remember more solicitous, conversation based nursing, today's task focused care can be a shock and disappointment.

For visitors too it can be difficult to know what to do. There are no offers to make (shall I pop the kettle on?), only that uncomfortable chair placed awkwardly alongside the bed in front of the locker with all sorts of barricades between you, and none of the prompts to conversation that can be found in a home. Thinking about it in advance would have enabled us to take a scrabble board, or a photo album, or just relax into *being* and *connecting* rather than *doing*. Hospices too? I know they sound more warm and cuddly than hospitals but some stays here too can be equally tedious, and the disappointment can be greater.

So the letter to me as a carer, no, the letter to me as a daughter, could have come from a mediation perspective: offering support in exploring with my mother how we could make this period of care, this time in our lives, as rich and valuable as possible for both of us. Helping us to negotiate our constantly changing reality.

A clinician's reflections

I started by noting Gawande's charge of obtuseness on the part of doctors, and I have expanded that charge to include us all. I've suggested we all need to undull our assumptions and remind ourselves that life is a process of learning how to live – a life-long process that includes learning how to live when we are dying. But there is an important part played in this by doctors, and their obtuseness is, I suggest, driven by a kind of squeamishness, that I can best illustrate by returning to the blog with which I started: the thoughts of Philip Berry.

Berry is someone I have never met but whose thoughts and reflections I have enjoyed and valued. I see him as candid and thoughtful and highly competent, as someone I would be pleased to meet in a clinical emergency. The assumptions underlying his written reflections are, I suggest, indications of attitudes much more widely held.

In his blog in response to Atul Gawande's third Reith lecture he writes

'Broadening the conversation to non-medical goals can feel risky at times. It brings the patient out from the usual transaction of therapeutic benefits and burdens, as though to say – *'These medical details are not relevant in the longer term, because you are gradually approaching the end, and there is nothing we can do to stop it...'* – Even in skilled hands, it is an intrinsically negative conversation, however one wants to portray the identification of goals as positive.

Here I feel Berry is confusing negativity and sadness. Sadness is *not* negative, and seeing it as that is a cause of squeamishness. Sadness is an essential part of our lives, I mean that literally, essential means a 'central part', a 'fundamental quality', an 'intrinsic nature' – from the Latin 'esse' – to be. Part of learning how to live is learning how to be with sadness, how not to push it away but tolerate it, accept it, and mourn what lies behind it as fully as that deserves. This is part of growing up – a part we are in danger of ignoring, and thus remaining infantile in our expectations of the world.

We don't do anyone any favours by denying them the opportunity to experience that sadness. This isn't negative, its rich and real. Life is a wonder and those of us who aren't in great suffering will be sad to say goodbye to it – but we want our farewell, the sadness of our farewell, to be honoured, not ignored. Berry's squeamishness prevents him and his patient from participating in this and offers no role model to juniors or to relatives. I think he is bigger than he is allowing himself to be.

Later he says:

Sue Lawley, who chaired the Reith lectures, …. asked the question,

'Doesn't the desire for life suddenly at the end, when someone is aware that they are dying, suddenly overcome all kinds of thoughts they might have had before? Suddenly people want to live.'

This is what I have seen in the eyes of patients who have been admitted for emergency care at the end of life. I see it in their relatives' eyes too. It is the strong desire for help. Yes, that might be help with poorly controlled pain or breathlessness (ie. emergency palliation) but in the ED, or on the acute ward, the first response of physicians is to deal with the active complication – be it a chest infection, haemorrhage or electrolyte disturbance. Salvage. *Not* submitting to nature, yet.

Resisting the impulse for survival is unnatural, for want of a better word, and in the context of a rapid or unexpected change in condition it is very hard for relatives, primary physicians, even hospice staff, *not* to refer to hospital – even if the patient's stated goals have made it clear that more time in hospital is the last thing they want. Once in hospital, escalation is often hard to avoid (I explored this in a post called '5 days: a tale of escalation creep')

Here help is certainly wanted but what kind: treatment for an 'active complication' or emergency palliation? That will depend, but if death has been discussed in advance, contemplated and accepted, then the care that is needed will often be *help with the fear*, the alarm, and not the complication.

Isn't it clinical squeamishness that prefers to deal with the complication rather than help the patient stay present with the fear and overcome or accept it? We can say that to do otherwise is 'unnatural' or we can aim to overcome our squeamishness here as we do when dealing with other unnatural acts such as cleaning up vomit or faeces.

Later, after describing Gawande's conversations with his own father about his goals as he neared the end of his life Berry continues:

The difficulty I experience is that this conversation often runs in parallel to the rather downbeat subject of 'ceilings of care.' For all the focus on goals and what can be achieved in their final weeks, fairly rigorous planning is required to agree on what will *not* be done. …… To disconnect the two ('I'll bring it up another time…') seems cowardly, but to move from goals to ceilings might appear callous – 'OK, we've explored what your priorities are… and in light of those we need to talk about what treatments might not be appropriate, should you be rushed in with something acute…' Again, the positive segues into the negative. The negatives *have* to be broached. And we don't find this easy.

Again I think Berry's hesitation is rooted in an assumption that 'care = interventions'. Whereas I see care as acts of work and courage that enable flourishing.

Deciding not to intervene is only negative if you see interventions as a good thing in their own right, or their consequences as desirable. Where the patient does not see either of these then it is intervening that is negative.

Again, what undoubtedly feels sensitive to Berry feels squeamish to me. But not so long ago it would probably have felt sensitive to me too, so I am not blaming but suggesting this is an assumption we can all usefully challenge.

In his last paragraph Berry talks of the need for doctors to be 'bolder but colder'.

The barriers described above are real, and exist not because doctors are too lazy or obtuse to surmount them, but because they find it difficult to find the 'right time' or the 'right way' to draw their patients into a conversation that they may not be ready for. It is a manifestation of over-sensitivity, rather than the opposite. ……To be better we probably need to be bolder – even if that means feeling a little colder.

And here I am with him completely about the boldness, I'd call it courage I think, and see that as integral to care.

Colder? I really hope not – this courage needs to be rooted in empathy, in compassion, in thinking wholeheartedly of the other person. So, not colder but more courageous, more caring, less squeamish, less obtuse.

Conclusions: How to lose our squeamishness so we can lead flourishing lives

So I suggest that Gawande is right: obtuseness on the part of doctors is a problem. It diminishes our ability, as patients, to treat our dying as the most grown up thing we will ever do and keeps us from the comfort they could offer that will help us to approach it with courage.

But an even greater problem is the obtuseness, the dullness, the self-imposed blindness of the rest of us. We all diminish our lives and choose not to prepare, as we could, for this most grown up of activities: we obtusely seek to make our lives as long as possible instead of considering how fully we can flourish.

So let’s not reject the charge but do something about it. What could we do?

Dying may be the most grown up and generous thing we ever do, but it is also, for each of us, an unprecedented event that takes us into the unknown. So we will inevitably need courage and will benefit from the comfort (being courageous together) of others. At the moment neither of these parties (patients and clinicians) is ensuring their preparedness, their fitness to do this.

Acknowledging our death enlivens our lives and makes our moments more precious. Ignoring it prevents that and allows us to squander them. Worrying about it diminishes them further. So perhaps actively acknowledging that we will die is the first step. But it is surely inextricably linked to the second: having confidence that there are ways of preparing ourselves for it. So we do all need to take an interest in the quality and nature of care at the end of life.

I suggest that all of the following warrant some attention:

1. Expanding the role of palliative care

There is increasing acceptance in other specialties that care is not enough, that we must try to get ahead of demand, and that we must use our specialist professionals to support care rather than be the sole providers of it.

What might those principles mean for palliative care? Alongside their support for those who are dying, they could help us all to acknowledge and prepare for our death at a much earlier stage in our lives. They could help us develop ‘inside-out’ approaches, especially those that take time to become familiar with. They could also help doctors and other health care professionals lose their squeamishness about talking with patients and families about dying, and help them feel able to offer us their care and comfort when we most need it.

2. Changing the current model of care for people in their last months of life

Care for many in thier last months is not only poor but expensive. A radical change is needed and a model of self managed teams involving paid and informal carers making it more humane and less expensive.

3. Supporting health care professionals so that they are emotionally able to discuss dying with us, and stop colluding with us in ignoring it

If HCPs can see dying as natural, essential, even generous, as well as sad and frightening, they may be better able to support us. That will be easier if they (and all of us) can see sadness as an essential, unavoidable, part of life. Even so they will need support if they are to find ways of honouring the sadness of others without being overwhelmed.

Where would the opportunity for such support be found? In Schwartz Rounds? in Balint Groups? These are both excellent but are not offered routinely, and not when such support is most needed. It might once have been within the remit of clinical supervision, but regrettably that is now more instrumental and governance driven and does not support, challenge and enable in the way it could and should. But I do believe this is the most effective form of support – revitalised, humane, supportive, challenging, enabling clinical supervision.

Personally I suggest action is needed in all of these directions, and it would be depressing and infuriating to hear clinicians or managers protest that they would love to do this but are frustrated by lack of resources. I hope I have convincingly demonstrated that their lack of preparedness to do this leads to ***huge*** waste of resources.

Perhaps the most important action of all is for all of us consider the question 'is dying the most grown up and generous thing we will ever do?' And then wonder how to live (and help others to live) in that knowledge.

A condensed version of this paper can be found in the August 2016 edition of the Journal Health Care Analysis