

# Finding meaning in the bureaucracy of bereavement



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Bereaved people find themselves with a long list of things to organise including legal recognition of the death, arranging for the disposal of body of the person who has died and dealing with their money and other affairs. There appears to be minimal research or attention given to these areas in bereavement literature, but they are a universal experience for the people most closely related to the deceased. This article by Anne Wade of the Bereavement Advice Centre seeks to identify and understand the meaning of these tasks – frequently regarded as onerous – based on the author's own experience of providing information, advice and signposting to bereaved people over a period of 20 years. Her contention is that better communication of the purpose behind administrative tasks can not only result in a better service, but also help bereaved people to find some meaning in the bureaucracy of death.

## Introduction

### ***The Bureaucracy of Death***

#### ***Do you know what to do when someone dies?'***

This was the title the Bereavement Advice Centre used in 2010 when we surveyed a wide range of professionals and volunteers, including those from Cruse Bereavement Care, involved in giving care during the end of life care/bereavement pathway. Our purpose was to test their knowledge of the practical tasks that need to be done after a death. Questions included the average cost of a cremation, the role of the coroner, how soon registration of death must be done and how long it takes to administer an estate. The surveys were completed in face-to-face encounters at conferences and presentations, and most respondents expressed shock at how little they knew. The only group with consistent knowledge was hospital bereavement officers, part of whose function is to impart this type of information to newly bereaved people.

It was precisely to help fill this gap in the end of life/bereavement pathway that the Bereavement Advice Centre had been created in 2007, as many bereaved families do not have access to hospital bereavement services. My own experience

providing early bereavement support in the NHS both within hours and during the first few days after a death had shown me that even when that support is provided, it is often too soon for families to have been able to formulate any question other than 'what do I need to do next?' Registration of the death or contact with the coroner's office are the most common immediate responses, followed by arranging a funeral.

The survey confirmed for us that the Bereavement Advice Centre did not duplicate any existing services in having a wide overview of all the practicalities encountered in bereavement so that we can give information, advice and signposting including to sources of psychological support.

## Finding a positive framework for death 'bureaucracy'

Television documentaries and dramas often deal with formerly 'taboo' topics such as end of life care, assisted suicide and funeral directing. There is a long tradition of drama with forensic pathologists and investigators in key roles, and a recent BBC series was based in the West London Coroner's service. Most of the respondents to our survey had a partially accurate idea of the role of a coroner. However registrars of death and professionals involved in the administration of probate seem mainly invisible, despite providing essential functions.

There is a perception that 'bureaucracy' is boring and the majority of the definitions I have found on the internet have unenthusiastic at best and often deeply cynical. I know in the past, probably in common with many people, I regarded what has to be done following a death to be a necessary evil – an imposition on people who need time and space to grieve, unimpeded by the requirements of the state, law and other institutions.

However, this does not make a great deal of sense. We all die and the overwhelming majority of us experience bereavement through death a number of times and will, sometimes, be the person with lead responsibility for making arrangements and dealing with the estate. It seems reasonable to assume, therefore, that the procedures currently in place originated with positive intentions and fulfil some useful purposes that have allowed

them to persist. However, I do also feel it is reasonable to claim that the traditional taboo around death means that it has taken tragedies at Bristol and Alder Hey hospitals and elsewhere, and the Harold Shipman cases, to overcome inertia and impel government to introduce necessary legislation to enable modernisation that make some of these systems fit for purpose in the current century.

Over the last five years, since leaving bereavement services in the NHS and learning far more about these practical issues, not just immediately after a death but through the following year or so, my own assumptions have been challenged and I have begun to search for a more positive understanding of what needs to be done after a death.

I initially tried using the medical ethics themes of beneficence, non-maleficence, autonomy and justice as these were familiar to me from my days in nursing and as a former member of a clinical ethics committee (Gillon 1993). However these did not seem to fit as there is little room for autonomy in procedures laid down in law. Therefore I searched for common themes that might underpin and account for the tasks required of bereaved people.

This is ongoing work and in some ways I still feel that I am scratching the surface. However, I have been able to map some of the key steps that need to be achieved practically such as investigation of the death, disposal of the body and administration of the estate under the headings: Prevention/Protection; Support; Justice; and Rights and Responsibilities.

Throughout the remainder of this article these themes will appear in brackets and in bold as I seek to illustrate how they apply. The definitions I have assigned to these titles are as follows:

- **Prevention/Protection: can be applied to a bereaved individual but also to wider society eg. prevention of future harm.**
- **Support: primarily processes that have an aspect that can be seen as supportive of bereaved people.**
- **Justice: processes that ensure compliance with the law, ensuring justice is achieved as defined by legislation.**
- **Rights and Responsibilities: closely linked with Justice, the law gives individuals certain rights after a death but there are also responsibilities both for those who are involved in the care of bereaved people and for those who are bereaved.**

Is this positive view of the tasks needing to be done merely something to help me feel more comfortable in my current role? I recognise there could be some truth in that. However, I would suggest that a better service is provided when information is given to bereaved people by others who understand both the facts of the information given, and the rationale behind them. How much better still if the people delivering the service also have an understanding of the possible specific effects of the information on bereaved people?

I cannot yet provide any evidence to support my contention that in-depth knowledge and understanding leads to better service

provision, and am unsure how it would be possible to do this in a way that would provide meaningful quantitative data. Neither would I wish to fall into the trap of claiming too great an impact on the longer term course of grieving of good or poor service in terms of information giving. I do know anecdotally that people have abiding memories both of unhelpful interactions and also intelligent kindness. People who provide this type of service, in whatever context, are pieces of a jigsaw of services available for bereaved people and all the other contacts they will be required to make. However the need for accurate and timely information is universal.

I certainly wish there had been someone to explain to me what I now know, 20 years ago. I continue to be profoundly grateful to all the bereaved people who are honest and brave enough to admit to their own lack of knowledge and the sense of disempowerment, confusion and loss of control that results. My knowledge has been gained as a result of seeking to respond to their questions and dilemmas. I also owe much to the professionals in all the death related sectors who have so generously shared their own knowledge over the same period of time.

### Establishing cause of death

It is a requirement of English and Welsh law that whenever possible, a cause of death is identified and recorded. In the past, in the NHS, I developed a regular 'script' for explaining to certain bereaved families that a coroner's post-mortem examination would be needed, even though the death appeared completely natural but unexplained. The script was that under English law everyone is regarded as sufficiently important and valuable that their death may not go unexplained. (The situation is the same in Wales and Northern Ireland but in Scotland not so much precision of diagnosis is required for a natural death.)

It is worth considering who are the interested parties – in a general sense, not the stricter interpretation of this phrase that might be used by a coroner. The people who are directly affected by the death may find it helpful to understand the truth of what has happened to the person they were bound to by ties of law and/or affection [**support**]. Calls to the Bereavement Advice Centre from people seeking clarification of the events leading up to the death (particularly related to medical issues) are usually timed from a few days up to about three months after the death. Our callers often articulate the need to understand, and state that this is an obstacle that must be surmounted before they can grieve in the way they feel they need to.

There can also be practical consequences arising from the cause of death, including medical implications for other family members if there is a genetic component to a condition [Prevention/Protection]. It may be that some person(s) is responsible for causing the death and ensuring they are subject to appropriate **justice** helps **prevent** avoidable deaths in the future. Avoidable deaths may also be **prevented** by epidemiological work analysing trends in deaths, or on a smaller scale by actions to mitigate risks or address failures of care. Rule 43 Reports are issued by coroners recommending action to

**prevent** similar deaths – these might be issued to a health or care agency when systemic failures have been identified. Another example is the report issued by the coroner after the inquest into the 7/7 terrorist attacks (HM Coroner 2011).

While it is difficult to assert that the person who died has **rights** in relation to their cause of death being known, I believe personally that this is an expression of the value that is placed on the individual within our society. Likewise everyone has a **responsibility** to inform the police or a coroner if they have relevant knowledge relating to a death that may not be natural. This will soon become a statutory duty for doctors.

However this creates dilemmas in a society that has become increasingly diverse in terms of ethnicity and belief. For some the need to bury an intact body takes priority even over gathering evidence for the prosecution of someone accused of murder or manslaughter. Therefore procedures that exist for good reasons can, to some, appear both discriminatory and deeply distressing. The rule of law currently overrides religious considerations but whenever possible efforts will be made to expedite procedures to reduce delays to funerals [**support**]. Some of the early research into non-invasive investigation of death using scanning technologies was funded by a faith group; a creative response to a conflict of interest that led to the Department of Health funding follow-up larger scale research (Roberts, 2011).

## Care of the body

How might the themes I have identified apply to care for the body of the person who has died and its final disposal? **Support** for the bereaved family is shown through respect being shown to the body by professionals entrusted with its care. The Association of Anatomical Pathology Technologists promotes high standards in mortuary care as a matter of principle (AAPTUK, 2012) as well as representing the professional interests of its members.

**Prevention** of distress to the general public is required in how bodies are moved. Certain diagnoses of highly infectious diseases require very specific care to **prevent** risk to public health. The latter is governed by the Public Health (Control of Disease) Act 1984 which also provides for local authorities to arrange funerals for people who die with no-one else to make arrangements for them [**rights/responsibilities**].

In 2011 new guidance, *Care after death* (NHS, 2011) was issued for health and care professionals. Among other points it includes (p2):

- Honouring the cultural and spiritual wishes of the deceased person and their family/carers while ensuring legal obligations are met.
- Offering family and carers present the opportunity to participate in the process and supporting them to do so.
- Ensuring the dignity and privacy of the deceased person is maintained.
- Ensuring the health and safety of everyone who comes into contact with the body is protected.

## Arranging a funeral

Funeral directors continue care of the person who has died under instruction from the bereaved family members. I have spoken with funeral professionals from other European nations who have expressed surprise at how much freedom people have in this country to make very individual funeral arrangements including burial on private land. There is considerable expression of creativity by both bereaved families and people working in association with the funeral industry [**support** and **rights**]. For example, the variety of companies providing dispersal of cremated remains in spectacular firework displays I believe originates from a caller to the Saturday morning Radio 4 John Peel Show who stated that this is what she would like to happen to her. A quick search of the internet shows Ghana could perhaps claim top spot for variety and colour in coffins, but a working model of a specific model of a Rolls Royce car was the chosen bespoke coffin for someone to be buried on his own land. The wheels had to function as it was too heavy to be carried to the grave.

However, people arranging burials on private land are expected to exercise care with regard to the proximity of water courses and utility services for their own safety as well as that of others [**responsibility**]. It is also expected that a record of the burial, including its location, be kept with the deeds for the property ensuring possible future purchasers can make a properly informed choices as well as avoiding alarming discoveries. In rural areas where land is passed down through generations of the same family, burial on private land is becoming more popular [**rights**].

It should be remembered that instructions given in a will about a funeral are not binding in the way that other instructions in the same document constrain the executor(s). A family or executor is not required to arrange a funeral that costs more than the funds available in the estate unless they choose to do so voluntarily [**justice**]. The moral here is that if I wish to be conveyed to my final resting place in a Victorian glass hearse drawn by ostrich feather-adorned caparisoned horses, I need to make provision for this. I also need to make sure I do not leave my estate insolvent as creditors who became aware of excessive expenditure on my funeral could pursue my executor for compensation from her personally on the grounds of maladministration of my estate. The law ensures a balance of the **rights** and **responsibilities** of various parties involved after a death.

## Informing people about a death

Historically, when most people lived and died within a limited geographic area and the majority lived a subsistence existence, everyone who needed to know about a death would have found out very quickly by word of mouth. We live in far more connected times as anyone who has moved house is soon reminded by the seemingly interminable list of people to be informed of the change of address and phone number. The loss of a mobile phone and its contact list or an un-backed-up laptop's email directory can leave us feeling suddenly isolated. How much more challenging when the person **responsible** for notifying all of our work-focused,

financial, property-related and social networks is not familiar with the complex web of connections centred on each of us.

Thus one of the tasks that can feel very daunting after a death is the long list of organisations that need to be informed. An organisation, once notified, has a **responsibility** to ensure that information is cascaded internally in an efficient manner. In one hospital in which I worked I discovered that the patient transport system was not connected to the main patient administration computer system (PAS). Therefore there had been one or two awful occasions when an ambulance had arrived at a front door to take the patient to an outpatient appointment at much the same time as the funeral cortege arrived. The problem was rectified with a simple list delivered on a regular basis together with a check of PAS to ensure no appointments were due prior to the next list being circulated. However, if the patient had died in another hospital there was no mechanism to notify us of the death unless the family remembered to inform us.

This illustrates at a very simple level that failure to notify a death appropriately may have harmful consequences for others. For example the freeing up of a hospital outpatient appointment for someone who may urgently need it.

A failure to act in a timely manner by a bereaved person can also have negative consequences for themselves. Overpayment of benefits into a joint bank account might lead to money being spent on funeral arrangements that will later be reclaimed by the Department for Work and Pensions [**prevention**]. A Registrar of Deaths may query a long delay before a funeral if this has not been previously advised (for example the funeral will be delayed to allow travel of mourners from overseas). One of the worst scenarios would be an executor incurring interest payments or even a fine because of late or non-payment of inheritance tax.

### Initiatives to reduce bureaucracy

Government has recently addressed the problem of the internal cascade of information through the introduction of the Tell Us Once (TUO) service (see box). Two of the important aspects of the TUO programme are that it is only implemented with the active consent of the person registering the death, and that the TUO system does not retain data – it acts as a conduit but then deletes data after quite a short period of time. Families appreciate the reduction in numbers of letters, visits and calls that have to be made [**support/prevention**] and central and local government achieves savings of taxpayers' money by reducing the number of contacts with people.

In other words the service is experienced as being **supportive**. Bereaved people are **protected** from accidentally using money that is not theirs to spend on the funeral and other items because timely notification of the death prevents overpayment of benefits to the deceased, which would then have to be recovered at further cost to the public purse. TUO is an example of a service that provides much greater efficiency behind the scenes with an improved service to the public.

Services to bereaved people have not been the sole concern of health and social care in recent years. Her Majesty's Revenue and Customs has consulted to improve the tone of its letters to

bereaved people and simplified some of its forms [**support**]. My experience of government departments is not of indifferent bureaucrats, but of individuals with a real care and concern to bring about change and improvement even in times of severe economic constraints, even if the pace of change is sometimes slower than many of us would prefer.

Financial organisations have also reviewed services to bereaved people. One significant change is that although banks and building societies could legally demand Grants of Probate to be obtained for all deceased estates with more than £5,000 in assets, the majority have voluntarily increased their thresholds to an average of £15,000 [**support**]. This simplifies the closing of accounts for bereaved families but also reduces administrative costs to the bank which would otherwise have to be recovered through charges to customers [**justice**]. Even so, just over half of people who die in England and Wales leave enough money or property that probate will be required. A small and simple estate with just two bank accounts may be resolved in a few months, but more complex situations may require a year or more especially where property is involved. In essence the process of probate is designed to ensure that the funeral is paid for appropriately, anyone owed money by the deceased is paid and that the people who are entitled to inherit do receive what the deceased intended for them, subject to the estate being large enough for all of this to happen [**justice**].

If there is insufficient money, then the law gives very clear instructions as to the priority in which debts should be paid. If a husband dies and leaves credit card debts on cards that were in his name alone, his widow does not inherit his debts [**justice**]. However if he was a tenant-in-common of their home, this may then be at risk or a sympathetic creditor may place a charge against the property so the debt is recovered at a future date when the property is eventually sold for whatever reason. This is a possible major secondary loss.

The law also **protects** the immediate family members in the situation of someone not having made a will. At the time of writing the first £250,000 of an estate passes by right to the marital partner. There is also provision in law for people who were financially dependent on the deceased to make a claim against the estate if they have not been recognised in a will or were not married or in a civil partnership with the deceased [**justice**]. This is a huge topic, but in a world where identity fraud is on the increase and family structures are often complex, fractured and sadly acrimonious, the process of probate and estate administration is very important to provide **just** distribution of the material legacies people leave behind.

Another example of services that meet more than one need are those providing suppression of direct mail, more commonly described as junk mail. The companies responsible neither want to waste resources with useless mailings nor do they want the damage to their reputation resulting from post addressed to people who have died. The benefit for bereaved people is that the service is provided to them free of charge and significantly reduces the distress and burden of inappropriate post as well as reducing the risk of identity fraud through theft of mail [**support/prevention/protection**].

## Conclusion

Any model of grieving that supports a view of it being overwhelming and incapacitating does not fit with my experience of newly bereaved people. Even in the hours and days immediately after a death many people, with the right information provided in the right way at the right time, are able to connect with their normal competent responsible selves and are able to carry out all that is required of them. This requires a balanced form of **support** that recognises and acknowledges the enormity of what has happened and creates space and flexibility for the full range of emotional expression experienced at these times, while still enabling people to engage with the world of police, coroners, doctors, bereavement staff, registrars and funeral directors depending on the circumstances of the death.

Bereaved people have much to do over and above their normal activities of daily living at the same time as they often have to relearn or learn for the first time some of those activities, especially when it is a life partner who has died or someone else in the immediate family group. This happens not as something

separate from their grieving but as an ongoing thread woven through the whole experience. There are reasons why this bureaucracy of bereavement exists and I hope that, sometimes, understanding the 'why' may lighten the sense of burden created by what has to be done. ■

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### Tell Us Once – government's plan to give precious moments back

Bereavement is a devastating time in anyone's life. Regardless of whether it's anticipated or unexpected, it is a time of great personal upheaval that presents us with challenges and emotions that we can never truly plan for.

It's also one of those occasions when people must deal directly with central and local government. Typically this has involved an endless array of paperwork and red tape that seemed to exist solely to make a difficult time for people even worse.

On average, a person suffering a bereavement would have to contact government seven times. In the very worst cases, that number escalated to more than 40. Either way, those who found themselves in the unfortunate position of having to notify the government of a bereavement were left to confront an ongoing saga of death certificates, demands and administration that left no room for understanding or compassion.

In 2007 Sir David Varney produced a report titled *Service transformation: a better service for citizens and businesses, a better deal for the taxpayer*. It prompted government departments and services to do some much needed self analysis.

The efficiency of the birth and bereavement reporting service was one service that went under the microscope, revealing a cumbersome process that had become so ingrained in government operations that for so long, no one had stopped to ask the question: Why are we making this process so difficult for people? From that question came the answer – Tell Us Once.

The idea is simple. A service that notifies the relevant government departments and services of bereavement in a single appointment. This can be done face to face, by phone or using the on-line service on the Directgov site. No more convoluted and repetitive government process, and no more red tape.

On making an appointment to register a birth or death, people are told about Tell Us Once and invited, if they wish, to use the service. Since September 2011, the average customer take-up for the bereavement service already stands at nearly 70% and is even higher in areas where the service is more established. The benefits to participants are huge. For those who have been bereaved they no longer need to worry about erroneously receiving their deceased loved one's pensions, only to have to pay back the money at a later stage. They also save money which would otherwise have been spent on duplicate birth or death certificates and phone calls and letters to the various authorities.

Tell Us Once is a bold and progressive recognition from central government that red tape does not belong in a moment of bereavement. People confronted with the despair of bereavement shouldn't also be confronted with over-bearing government rigmarole. Tell Us Once is about government giving those moments back to people. It's about allowing bereavement to be exactly what it is: a moment in life that belongs solely to those experiencing it.

Tell Us Once is currently being offered by most of local authorities in England, Scotland and Wales. An online service was launched in April 2012. But there is much more to achieve.

There are more authorities and partners to join up with and offer more benefits to people who need help in the most difficult of circumstances. The Tell Us once model is also being investigated by governments in Australia, New Zealand and Canada. The pain of bereavement is universal and we are confident that the service can continue growing and helping people who face it and the impacts it can have on your life.

More information is available at [www.direct.gov.uk/death-tellusonce](http://www.direct.gov.uk/death-tellusonce)