Care of the body in funeral directing services

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Contents

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Introduction

Introduction

A principal task of funeral directors is to deal with the remains of a person who has died, and to do so in a way that conforms to the wishes of the family arranging the funeral. This task is fraught with complication: funeral directors may be less than transparent about how exactly the body is cared for after death; families vary substantially in the degree to which they are emotionally invested in the body of the person who has died and in their tolerance of details as to body preparation; and there are subsequent difficulties with families and funeral directors arriving at effective dialogue where information is shared and active choices are made. Securing the right level of contact with the deceased after death is integral to satisfaction in the funeral, which increases the importance of getting this element right.

This introductory section presents some background factors that have framed the need to give greater consideration to industry practices and family decision-making relating to care of the deceased after death. The research combines a review of industry documentation, quantitative survey work with funeral directors and qualitative interviews with members of the public who have arranged a funeral. It should be stressed from the outset that this research has taken place *during* the Covid pandemic but that respondents have reflected on *pre*-pandemic funerals.

Background

The research has taken place within a context of heightened understanding of the economics of the funerary industry following a Competitions and Market Authority (CMA) investigation; increasing interest on the concept of 'direct cremation' providing a simpler funeral format; and the impact of the Covid pandemic in focussing attention on what is valued in funeral practice. This report also draws substantially from earlier findings published as *Funeral Experts by Experience: What Matters to Them*, which undertook a detailed qualitative exploration from the perspective of people arranging, participating in and attending funerals.

CMA investigation into funeral services
In 2018, the Competition and Markets Authority (CMA) began a scoping exercise to examine the funeral directing industry, with a view to establishing whether the purchaser of funeral services is buying from a market where transparency ensured that those services were priced competitively. The CMA investigation focussed on both the funeral purchase and on crematoria pricing. The CMA's final report was published in December 2020 and a Funerals Market Investigation Order, tightening regulation of the sector, was issued in June

2021.[1] The investigation engendered debate about transparency, quality and pricing structures in the industry. The particular focus on transparency provokes questions on exactly what information is needed by the funeral consumer in order for them to make an informed decision on what they are purchasing. For the CMA, this information is essential in order for consumers to be able to undertake effective price comparison and thereby increase competition in the funeral market with the effect of containing price increases.

However, in seeking a commitment to transparency, the CMA has tended to stress price transparency over service transparency. In seeking price transparency, the CMA is promoting informed customer choice. However, the CMA principles of transparency and informed decision-making should – in theory – also relate to the choices made with regard to care of the body after death. One of its recommendations makes reference to a standardised price list which includes, as a price heading, *Appropriate arrangements for the uplift of the deceased and care of the deceased person prior to the funeral in appropriate facilities.* The list also includes *Embalming (if offered*) as an additional service that should be listed separately. 'Care of the deceased' is given no definition, and the inclusion of embalming as an additional service infers that a clear line can be drawn between lesser and more invasive body preparation techniques. Transparency must therefore include, at the very least, a clear understanding of the services being offered.

Reviewing the issue in this light takes the principle of 'transparency' into the more complex realm of informed consent, which becomes difficult to secure in relation to an aspect of funeral directing practice that some individuals simply do not want to consider. On this area, the CMA final report is generally silent.

Direct cremation

A second key context for this research has been the development of a mode of funerals that has been termed 'direct cremation'. Definitions of direct cremation have not been fixed, and the package of services that are badged as 'direct cremation' can differ from funeral director to funeral director. However, in broad terms, direct cremation can be defined as a funeral which takes place without the participation of the family. The body is collected from the place of death by the funeral director, who then arranges a cremation which is not attended and where there is no service. Family members choose whether or not they want to collect the cremated remains.

Direct cremation is generally discussed in largely positive terms, as a strategy for families to reduce funeral costs. However, little attention has been paid to the fact that direct cremation removes the ability of families to interact with the body in any way after the death, including visiting with the body at the funeral director premises in the period between the death and the cremation. Again there are issues relating to informed choice: a family taking this option might well be left unaware of comfort and consolation they might derive from interaction with the person who died and this in turn could reduce funeral satisfaction and adversely impact on long-term wellbeing outcomes.

[1] CMA (2020) *Funerals Market Investigation*, London: CMA. Available at: https://www.gov.uk/cma-cases/funerals-market-study#final-report; CMA (2021) *Funerals Market Investigation Order*, London: CMA. Available at https://www.gov.uk/cma-cases/funerals-market-study

Effect of the Covid pandemic

A third essential context is the impact of the Covid pandemic. Dismay and distress relating to social distancing restrictions in hospitals and at funeral services have underlined the importance of ritual activities after death. Discussion has tended not to dwell on the fact that the Covid pandemic has also restricted the opportunity to tend the body and visit in funeral director premises. Family resourcefulness in framing new funerary rituals during the Covid pandemic have in some senses augmented views that direct cremation can be regarded as a generally acceptable model.

Funeral Experts by Experience – What Matters to Them?

The qualitative research study *Funeral Experts by Experience: What Matters to Them?* was published in September 2019.[2] This report was based on interviews with 50 respondents talking in detail about a funeral they had arranged, participated in, or attended. The interviews explored, in a very open way, what mattered to people when it comes to funerals. The research found that there were five main 'funeral factors' which people consistently reported were important to them, and which had an impact on their funeral experience and satisfaction. These factors were:

- Whether the wishes of the person who has died were known;
- Whether funeral related decision-making was felt to be inclusive;
- Whether the funeral directors had the right level of responsiveness to their needs;
- Whether time spent with the body met their needs; and
- Whether the funeral service itself was deemed to be satisfactory.

Achieving the right level of contact with the body was central to respondents defining satisfaction in the funeral overall. Individuals differed substantially in the comfort they derived from being with the body of the person who has died and so 'right level of contact' might mean that the person had no contact with the body at all, or that people had felt able to interact with the body after death principally through washing and dressing and spending time with the body at the funeral director's premises. Even where individuals did not engage in this level of interaction, there was a clear desire for the body to be treated with respect and solicitude: the person who died had to be 'comfortable'.

In questioning people about what they had found comforting with regard to care of the body, some respondents described feeling distressed by what they regarded as unnatural preparations including embalming and the way in which the facial features were prepared for viewing. No active consent is required for these treatments to take place. Further, respondents did not always understand what 'embalming' meant and distress could follow where respondents realised they had consented without being fully informed.

These background contexts indicate a lack of clarity on the principles that should guide care of the body after death and indicate tensions and inconsistency within current debates relating to the sector. As it currently stands, a call for transparency does not encompass the more active process of securing of informed consent, and this is particularly important

[2] https://eprints.whiterose.ac.uk/162914/1/FINAL_REPORT_Funeral_Experts_by_Experience.pdf

where there may be limited understanding of how bodies are dealt with by the funeral director. Industry guidance is limited on the ways to secure effective dialogue, and funeral directing practices are widely disparate. Direct cremation carries an increasingly normative presumption that families do not need direct contact with the body after death. In actuality, viewing the body and in taking part in elements of care are hugely comforting to many people.

Research questions

These contexts and tensions provoke the need for further exploration of the care of the body in the 'post-mortem interval' between the death and the funeral service. There is a general lack of understanding about what takes place during this period and how 'care' is defined and delivered by funeral directors. In addition, there has been limited exploration of the level of consent secured for certain types of body preparation, support for the family visiting the body at the funeral director, and the degree to which families are able to make active and informed decisions.

This report considers the following research questions:

- What happens to the body in the post-mortem interval?
- What training is available to funeral directors in body care and supporting family decisions around body care during the post-mortem interval, and what principles drive that training?
- To what degree were families involved in decisions about what happens with the body in the care of the funeral director?
- How do funeral directors prepare and support families visiting the body?
- How is the funeral director's treatment of the body judged by respondents?

Methods

The research questions were answered using a mixture of methods, including industry document analysis, a quantitative on-line survey of independent funeral directors and qualitative semi-structured interviews with respondents who had been involved in a funeral.

Professional literature review
Between June and August 2020, literature was obtained regarding funeral director training, guidance and practice. This literature included any training courses available to funeral directors and the published Codes of Practice of the two principal Trade Associations: The National Society of Allied and Independent Funeral Directors (SAIF) and The National Association of Funeral Directors (NAFD). Reference is made to the Funeral Services Consumer Standards Review Code of Practice, which was in development during the course

of the research and approved in February 2021.[3] The literature also included the Scottish Government's draft Code of Practice for Funeral Directing, which has had some impact on the tenor of English industry guidance.

In this report, all publicly available documentation – principally, the Codes of Conduct – will be referenced. Quotations will also be taken from other industry training manuals but reported anonymously using a unique identifier code.

Funeral Director survey

The research sought to understand what might be regarded as the 'usual' practice of independent funeral directors. Funeral directors working for the larger UK funeral director companies (Dignity and The Co-op Funeralcare and Funeral Partners) must follow operating policies and procedures regarding care of the body so their individual views and practices were not sought as part of this study.

Funeral directors were asked to participate via an anonymous online survey. The survey sought to ascertain the process of events from the funeral director perspective, and aimed to understand the points at which information is shared and consent secured. The survey also asked for the funeral director's views on family involvement in washing and dressing. The survey structure and questions were approved and overseen by a multidisciplinary research committee, including industry representatives from the Institute of Cemetery and Crematorium Management, SAIF and the Good Funeral Guide.

This survey was administered during July and August 2020. The pandemic had a significant impact on funeral director practice, and the survey asked funeral directors to reflect on their standard practices prior to March 2020. Funeral Directors opted in to complete the survey by accessing the survey and completing it online, or by answering the questions on the telephone with one of the research team completing the online survey for them. Information about the survey was made available on online funeral director's forums such as the Good Funeral Guild and the UK Funeral Forum on Facebook and information was shared by SAIF, The Good Funeral Guide and the ICCM. There were 272 respondents and information about respondents is summarised in Appendix 2.

Qualitative interviews with people who had arranged a funeral

In June 2020, with approval and oversight from the research committee, members of the public were invited to participate in a qualitative study to establish their ideas, concerns and expectations about how a body is cared for once it is in the care of a funeral director. Participants were over 18 years of age, and had attended or arranged a funeral in the UK before the global Coronavirus pandemic. The pandemic has had a significant impact on care of the body and this study seeks to understand 'usual' experiences outwith a pandemic context.

[3] The Funeral Services Consumer Standards Review was set up in May 2019, and aims 'to improve quality, standards and outcomes for funeral consumers'. Its secretariat is run jointly by SAIF and the NAFD. See http://www.fscsr.co.uk/

Participants opted in to the research by responding to a flier (see Appendix 1) which was emailed to the participants of a previous research study who had consented to further contact. Information about the study was also distributed via the Leeds Bereavement Forum and the social media channels of SAIF, the Institute of Cemetery and Crematorium Management, the Good Funeral Guide and Full Circle Funerals. Newspaper articles regarding the study and encouraging participation were published in local newspapers including the *Wharfedale Observer*, *Funeral Service Times*, *Holderness Gazette, York Press, Telegraph and Argus* and *Wharfedale Observer.*

Interviewees were invited to talk about funeral experiences prior to the beginning of the Covid-19 pandemic, in order to isolate 'typical', non-pandemic experiences. The interview schedule is reproduced in Appendix 1. The interviews took place via on on-line platform or by telephone during June and July 2020. Summary demographic information on respondents is available in Appendix 1. No attempt was made to solicit a representative sample, and the majority of respondents (27) were White British (see Appendix 3). It is evident that further research needs to be undertaken with a wider demographic selection in terms of ethnicity, and it is acknowledged here that the findings from the report are more representative of a White British and largely Christianised world view. The vast majority of respondents lived in England at the time of the interview, and – given the nature of localised recruiting – a large proportion was living in the Yorkshire and Humberside region.

From the outset it was made clear to respondents that the interview would ask specifically about what happened with the body of the person who had died. Respondents were asked themselves to choose a funeral to speak about, and were not directed to discuss experiences that were particularly good or particularly bad. No information was collected on the type of funeral director used by the respondent, since the objective of the research was not to comment on difference in experience between the larger corporate funeral directors and those who operate independently.

Ethics

An ethical approval process commensurate with a formal University ethics procedure was closely adhered to and included due regard for formal protocols of recruitment, informed consent, researcher and respondent mental health, and data protection. The research committee provided scrutiny and assurance. All qualitative respondents were informed about the nature of the study prior to data collection and actively opted in by signing a consent form. Project information is reproduced in Appendix 1.

Interviews with members of the public were undertaken by funeral directing staff using a topic guide that was agreed by the research committee. Interview transcripts were regularly reviewed as the research period progressed. Individual respondents were informed that the interview was likely to dwell aspects of the funeral they might find distressing. At multiple points during the interview respondents were given notice that difficult questions were coming up – for example, on invasive body procedures. As will be seen in Part Two, respondents made clear where their tolerances sat with regard to the degree of detail they were prepared to discuss, and those boundaries were respected.

Report structure

The report is structured in two major parts. Part One concentrates on care of the body from the funeral director perspective and integrates a narrative of care, reference to funeral directing training manuals and Codes of Practice and quantitative survey responses. Part Two turns its focus to the qualitative experience of people arranging funerals. This second section discusses four key contexts framing decision-making around care of the body: religious requirements; attitudes towards dead bodies generally; the death-bed and immediate post-mortem activity; and the mode of death and coroner involvement. The section discusses family involvement in decision-making and family evaluation of funeral director services as they relate to care of the body.

Finally, it is appropriate to give a note on terminology. Within the industry and in the context of direct contact with the bereaved it is highly unlikely that a funeral director would use the term 'dead body' in referring to the person who has died. Rather, practitioners are more likely to use the name of that person who has died or reference the relationship, ie 'your Mum'. Within practitioner-facing industry literature, the tendency is to use the term 'the deceased'. This term does not always denote a reference to the material remains of an individual, and as a consequence this report will use the less ambiguous term 'dead body'. It is notable that qualitative respondents themselves often used this term in unprompted ways, as indicated in quotations used in the report.

Part 1: Care of the body from the industry perspective

Introduction

The principal focus of this study is care of the body in the post-mortem interval, and this part of the report reviews the issue from the perspective of the funeral director. The section addresses four of the primary research questions:

- What happens to the body in the post-mortem interval?
- What training is available to funeral directors in body care and supporting family decisions around body care during the post-mortem interval, and what principles drive that training?
- To what degree were families involved in decisions about what happens with the body in the care of the funeral director?
- How do funeral directors prepare and support families visiting the body?

Funeral directors are not required to complete formal training, and generally learn 'on the job'. This section reviews some of the industry guidance which relates to care of the body during this period. The section also draws on findings from a quantitative survey of 272 independent funeral directors, who were asked about their practices with regard to care of the body. This part of the report concludes that guidance is opaque and funeral directors tend to act according to their own understandings of what may or may not be appropriate.

Training and guidance

In England, there are no government requirements that require funeral industry professionals to have received any formal training. In addition, there are no 'entry-level' qualifications required in order to begin work as a funeral director. There are two major representative bodies with a large minority of members belonging to both. The National Association of Funeral Directors (NAFD) – which represents independent, major and corporate group business – offers a Diploma in Funeral Arranging and Administration and a Diploma in Funeral Directing in conjunction with the University of Birmingham. The National Society of Allied and Independent Funeral Directors (SAIF), which tends to represent non-corporate operators, offers training via the Independent Funeral Directors' College. Members are advised to take up these training opportunities but neither training nor membership of a professional organisation is compulsory. In addition, it is not compulsory to complete the training and examinations required to become a member of the British Institute of Embalmers.[4] Essentially, anyone can set up a funeral directing business.

Currently, only Scotland has compulsory regulation in place: s97 of the Burial and Cremation (Scotland) Act 2016 requires that funeral professionals adhere to a Code of

[4] J. Rugg and B. Parsons (2018) *Funerary Practices in England and Wales*, Bingley: Emerald Publishing.

Practice which is currently in development and available in draft form. In England, professional representative bodies have produced voluntary codes of conduct and deliver training to members: much of a funeral care professional's training is developed 'on the job' and led by more experienced staff.

This section will explore events relating to the body in the post-mortem interval, and combines reference to documents produced by the industry and findings from the funeral director survey. The literature includes the public-facing Codes of Conduct published by the NAFD and SAIF. The team was also given access to industry-produced training literature, and this will be reported anonymously.[5] In addition, this section includes reference to the draft Scottish Government Funeral Director Code of Practice as an indicator of variation in the degree of detail and emphasis afforded different aspects of service. The discussion indicates an apparent absence of any guidance around some aspects of practice.

All codes of conduct place great emphasis on dignity in delivering care of the body at all stages in the post-mortem interval. The NAFD Code advises members to *preserve the dignity of deceased people in your care at all times.*[6] Similarly in Scotland, *funeral directors must ensure that the deceased is treated with care and dignity*.[7] The SAIF Code does not make any direct reference to care of the body but, rather, stresses that '*Members must conduct themselves in a totally professional manner, and behave sensitively, with courtesy and complete dignity at all times'*.[8]

Treatment of the body in the post-mortem interval

This report is concerned with the degree to which the family is actively involved in decision-making around care of the body once it has been removed to the funeral director's premises. As will be seen, industry literature signals that transparency and active consent for certain procedures are important principles that the funeral director must respect. In actuality, guidance can be opaque or absent on when and for what consent should be sought. The degree of discretion means that funeral directors tend to devise their own practices and procedures.

One of the principal difficulties in discussing the issue is the absence of a clear narrative of what exactly happens to a body from the point at which collection takes place, and a lack of certainty around definitions of terms such as 'hygienic preparation'. An unwillingness to dwell on details challenges notions that the service delivery should be transparent. This part of the report will discuss the principal body-related activities which include: collection of the body; storage at the funeral director's premises; and activities that are variously described as 'first offices', 'hygienic preparation', embalming, and posing the body; and facilitating family visits. Within the category of potential body treatments, all elements will be discussed aside from the detail of embalming techniques. Industry literature generally

[5] Some organisations did not grant access to their training materials.
[6] NAFD, *The Funeral Director Code*, 2020, Outcome 3.1. Note that a new NAFD code was in development as this report was being prepared.
[7] Scottish Government, *Funeral Director: Code of Practice*, 2019, 6.
[8] SAIF, *Code of Practice 2018*, 1.1.

refers to the purchaser of the funeral as 'the client', which will be echoed in quotations given, below.

Collection of the body

Once a funeral director has been appointed by a family and the necessary statutory processes have been completed, the funeral director will arrange to bring the person who has died into their care. Collection may take place from a domestic residence, in which case training manuals indicate that the client is asked *whether anyone would like to pay their last respects before removal effected. If this is requested, make sure the deceased is lying in a peaceful posture and if necessary carry out 'first offices'*.[9] One manual indicates that, in a domestic setting, this activity might include closing the eyes and mouth and cleaning the face, tidying the hair and cleaning up the surrounding area including wrapping up possibly soiled sheets and folding any removed clothing.

Funeral director survey returns indicate that funeral directors are generally prepared for a range of potentially problematic circumstances in effecting collection, including confined space within a bedroom, difficulty in negotiating stairs, and the possibility of a larger body. Indeed, funeral directors tended to make a judgement on the exact mode of collection on arriving at the premises, with the objective of securing an efficient and a dignified removal in the circumstances as presented.

The body is often removed using a rigid frame or stretcher, combined with some sort of covering material. Funeral directors often bring a sheet to wrap around the body, although in some cases they might use the sheet that the person is already lying on so that there is no need to slide or transfer the body. The body is completely wrapped and may be placed in a body bag or another similar kind of carrier. The funeral director is likely to use a stretcher suitable for use in a confined space: a 'first call' stretcher is light but robust and can be folded in half. A 'cricket-bag' style stretcher, often used for first-aid rescue, is made from canvas and has carry straps: where circumstances dictate the use of this style of stretcher, effort is made to transfer the body to a rigid, formal stretcher as soon as possible. The body may be covered by a coffin 'shell' before being transferred to the vehicle.

Collection of the body can be a difficult procedure: dead bodies are difficult to lift and manipulate, and the mode of death may mean that there has been some leakage of bodily fluids. Both these elements may be upsetting for the family to see. One training manual acknowledges that *witnessing the deceased being taken from the family home, […], can be most distressing.*[10] Another indicates that *it should be suggested to persons present that they may prefer to wait in another room whilst the deceased is moved*. This encourages people to leave but gives them the option to stay if they wish.[11]

The funeral director survey asked the respondent's views on family/friends being present during the collection of the body. Sixty per cent had no preferences, and 23 per cent indicated that they would discourage family/friends being present or regarded their

[9] Training Document #1, 8.
[10] Training manual #2, 6.
[11] Training manual #4, 7.

presence as inappropriate. Seventeen per cent of respondents indicated that they would encourage friends/family to be present and involved.

Storage

In England, there are no legal requirements relating to the storage of bodies at a funeral director's premises. In this regard, there is a marked contrast between requirements set out in the draft Scottish Code of Practice and rather more vague English guidance. In Scotland, there is a requirement that *care of the deceased must take place in a location(s) specifically chosen for that purpose*. To *ensure that their care facility or mortuary is fit for purpose*, the Code goes into detail about storage: premises should be lockable; maintain a high standard of hygiene and be regularly inspected; be suitable for purpose; and be so organised that the funeral director can access all necessary equipment, which should be well maintained.[12] The guidance offers flexibility in choice with either *a purpose built refrigeration unit or temperate controllable cold room*, and there are further details provided about temperature and capacity ratio.[13] Similar requirements are included in NAFD guidance. The SAIF Code of Practice simply requires that *there must be well-appointed and well-maintained areas and facilities for the preparation of the deceased and the holding of bodies*.[14]

Manuals tended to lack detail. One simply stated that, should a relative want to visit the deceased in these facilities, *everything would be found to be seemly and hygienic,* and the funeral director should simply aim to have a *properly equipped preparation room*.[15] In another, the guidance was even less explicit: *where possible transfer the deceased into a temperature-controlled environment*.[16] Just over two thirds of the survey respondents indicated that they used a fridge located in their own branch. Less than a tenth used refrigerator facilities located in another branch, and around a quarter used either a cool room or a 'cool area' at their own premises.

Codes of Practice also point towards regular checks on the body during the period between reception at the funeral director premises and the day of the funeral service.

'First offices', 'hygienic preparation', embalming and posing the body

Most funeral directors complete 'first offices' immediately after someone arrives in their care (noted above). These activities include placing a block under their head, closing eyes and mouths and massaging or swaddling / wrapping a body to affect its posture and positioning and wrapping the body in adsorbent materials to manage transfer or bodily fluids. Eye closure often includes inserting an 'eye cap' under the eyelids to compensate for the eyelid sinking, and perhaps adding glue to ensure that the eyes remain closed. Industry manuals generally regard a suture as the best method for keeping the mouth closed, providing the stitch does not impinge on the lips and affect the facial expression.

On reception at the funeral director premises, washing of the body often takes place using products that would not be appropriate in life, such as disinfectant, although in some training manuals indicate that the family might be asked to provide toiletries used by the

[12] Scottish Government, *Funeral Director: Code of Practice*, 8.
[13] Scottish Government, *Funeral Director: Code of Practice,* 10.
[14] SAIF, *Code of Practice,* 7.4.
[15] Training manual #2, 14.
[16] Training manual #4.

person who died. Industry manuals generally give detailed guidance on how to wash the body: for example, one manual indicates that the process of washing the deceased begins with the face and follows the hands, arms, legs and torso using warm water and mild disinfectant. The inside of the nose and mouth are also cleaned using mild disinfectant and then packed with cotton wool (unless the deceased is going to be embalmed). There is an emphasis on cleanliness of the fingernails, as hands are generally made visible on placing the body in the coffin. Hair is washed if it is deemed necessary by the practitioner.[17] Another manual gives similar guidance, but places greater stress on how the body should be moved to avoid cuts, scratches or other damage.[18]

The funeral director survey sought to find out what actions were actually taken by respondents once the body arrived at their premises. This proved to be a very difficult question to ask. The survey provided a small selection of options, but many funeral directors chose instead to add text to an open box and this revealed wide variety in practices and attitudes. One element of consensus was the need to position the head to ensure that the mouth was closed (80 per cent), and to effect non-invasive eye closure (75 per cent). Sixty-three per cent indicated that they would wash the hands and face only, and 64 per cent indicated that they would also apply cream to hands and face.

Beyond these actions, the kind of response varied substantially. A small number of respondents indicated that they did not begin any treatment at all until the death registration certification had been received, and simply kept the body covered in cold storage until that time. One respondent was of the view that no procedures were legal until the death certificate had been received: delay was deemed necessary to accommodate the possibility of a coroner investigation. For some respondents, first actions depended very much on the condition of the body coming into their care. In some instances, where the body had come from a medical facility, nursing or care staff may have already undertaken first offices and so it was felt that no further work needed to be done. Limited actions were also deemed necessary if the body was in such a poor state that the family was unlikely to view.

A very small proportion of respondents (4 per cent) indicated that their actions depended on family wishes. For many, actions depended on whether the family was likely to visit or if the body was going to be embalmed, and these responses indicated that some consultation had taken place with the family. However, in a number of cases the funeral directors' first response was to begin more invasive procedures including suturing and embalming.

In this report, an 'invasive procedure' is defined as any procedure that would only be carried out on a dead body and which includes the funeral director actively breaching the skin or any bodily orifice. This may include invasive methods of eye and mouth closure such as the use of sutures or insertion of 'eye caps' to compensate for sunken eyelids; wadding or packing absorbent granules into orifices; bursting intact blisters; and removing pacemakers. Embalming is by far the most invasive procedure, and involves removing the blood and replacing it with a proprietary embalming liquid.

[17] Training manual #4.
[18] Training manual #3, 6.

The fact that so many funeral directors commenced quite complex procedures from the point at which the body arrived at their practices means that it becomes difficult to distinguish between 'first offices' and 'hygienic preparation' if definitions in any way rest on the degree of invasion. Clarification on definitions is not evident in Codes of Practice. The draft Scottish Code of Practice indicates – under points 16 and 17 – that '*first offices must take place in every case, unless the client has specifically requested that first officers are not to take place'* and *Where first offices have not taken place, the funeral director must have a record of the reason/s for this*. The FSCSR code follows the draft Scottish Code of Conduct in presuming that first offices should take place *unless there is a good reason for not doing so*. In this case, a definition is given in the Code glossary: *The process of making a person who has died look presentable for loved ones to view. As a minimum, this will include cleaning and washing the body, dressing them and closing the eyes and mouth.*[19] There is ambiguity here. The definition defines a minimum, and does not preclude the use of more invasive procedures.

The industry manuals offer detailed guidance on the way in which the body should be presented, should the family wish to visit. Presentation follows the deployment of non-invasive and invasive procedures. One industry manual indicates that the object of preparation should be to achieve the most natural appearance, with a 'checklist' that includes *appearance of the facial features (ensure eyes and mouth are closed); skin tone and colouring, appearance of hands; hair is tidy; head is correctly postured; presence of odour/ leakage.* The manual indicates that, if the family agrees, a man's facial hair is shaved and massage cream is applied to avoid dehydration. It is advised that family input is also required to guide how the deceased's hair should be styled, as well as for the application of cosmetics. However, family agreement is not necessarily sought for closing the mouth using a suture, which is often recommended as the best method. The aim is to *not produce a pulling or pinched appearance of the mouth*. Eye caps are used to compensate for eyelid sinkage, and should not be visible.[20]

This manual indicates that the funeral director should follow the client's wishes when dressing the deceased. Detailed stages are outlined depending on whether the deceased will be dressing in a dressing gown or their own clothes. Other personal effects, such as jewellery or rosary beads, are also laid out with the deceased if requested by the client.[21] No information or guidance is given on asking the family if they would like to be involved in dressing the body or the practicalities of working with the family on this task.

The industry manuals give a great deal of detailed information on posing the body in the coffin, stressing the importance of the final image:

> *Bear in mind that the family and friends will have lasting memory following visiting the deceased in the Chapel of Rest – what they see will make or break their impression of you and will haunt them for the rest of their lives, if what they see comes as a shock.*[22]

[19] Own underlining. http://www.fscsr.co.uk/fscsr-code-of-practice-guidance/#code
[20] Training manual #4, various pages.
[21] Training manual #4, 6.
[22] Training manual #3, 6.

Again oral sutures are recommended as being *easily applied and [...] invisible*.[23] When making the final checks, a natural appearance is emphasised. This prioritises posing of the head, features, arms and hands. Particular detail is paid to how natural hand and finger placement can be achieved as these are considered to be expressive.[24] With regard to guidance on hair and makeup, the manual simply indicates that intervention should enhance the appearance of the deceased. Another manual also stresses the importance of hand placement: these should be *left visible outside the gown and folded across one another*, and it is recommended that a flower be placed between the hands to enhance the presentation.

The technical act of embalming is perhaps the most extreme intervention and takes place in an estimated 50 per cent of all funerals.[25] One industry manual includes material which helps the funeral director to convey the advantages of embalming to the family including stressing that embalming enables the presentation of the deceased 'as if they are at rest, with their dignity restored to them'.[26] The draft Scottish Code of Practice indicates that informed and written permission must be secured from the client before embalming can take place. Reference is often made to the British Institute of Embalmers own Code of Practice which apparently requires that families must give consent to the procedure in writing.[27] However, terminology again can prove to be problematic. It is common for the industry to use the term 'hygienic treatment' as a synonym for embalming, which may create confusion since this term might also apply to first offices. Indeed, one manual acknowledged the confusion that can arise and stressed the need for clarity with the family.[28]

Facilitating family visits

Family visits to the funeral director's premises to view the person who has died are regular occurrences. Table 1.1, based on responses to the funeral director survey, indicates that 79 per cent of respondents saw visits taking place either half the time or more than half the time. The industry documentation reviewed in this report regards these visits as generally beneficial to clients.

Table 1.1 How often do people choose to visit people in your care?

	Number	Percentage
Rarely	8	3
Less than half the time	49	18
Approximately half the time	81	30
More than half the time/most of the time	134	49
Total	272	100

[23] Training manual #3, 7.
[24] Training manual #3, 9.
[25] Rugg and Parsons *Funerary Practices in England and Wales,* 97.
[26] Training manual #1, 113.
[27] The British Institute of Embalmer 'Code of Ethics' includes no such guidance: https://www.bioe.co.uk/about/
[28] Training manual #1, 113.

The Codes of Conduct indicate that funeral directors' premises should contain areas suitable for friend and family to, in the words of the SAIF Code, '*see the deceased and pay their respects in suitably tranquil and private surroundings*'.[29] Similarly, the draft Scottish Code requires visiting areas to be '*fit for purpose, private, clean, regularly inspected and well maintained*'.[30] Training manuals include detail on the way in which 'chapels of rest' should be presented including guidance around lighting and facilities. One manual includes extended information about how the funeral director should guide family and friends through the visit, including offering a preparatory chat with tea or coffee to explain what the visitors are going to see, being 'on hand' and present as the family exits the room again to be able to offer support and space if needed.

The Code of Practices and industry guidance is generally alert to the possibility that there may be circumstances in which viewing the body is not advisable. The funeral director should '*gently discuss this with the client*' and suggest that the visit take place with a closed coffin.[31] The draft Scottish Code of Practice similarly suggests '*sensitively worded advice setting out their reasons'*, but also keeping a record of the advice given.[32]

Discussion of body treatments with the family

Industry documentation generally refers to 'transparency' as a guiding principle, in the sense that all services are clearly explained and itemised on the final bill. The SAIF Code states that *members must establish and interpret client needs without exploiting their vulnerability or exerting any pressure on them*. As part of this, they *must explain their full range of services relevant to the particular client*, and in written estimates includes a price breakdown of treatments such as embalming/hygienic preparation.[33] The NAFD Funeral Director Code requires it members to give *clients and prospective clients sufficient information to allow them to make informed decisions about the services they need and the options available to them*.[34] In Scotland, practitioner *must be transparent with the client about the goods and services they offer.*[35] It is notable that in this guidance clear information around treatments such as first offices however should only be provided if requested by the client, and should be done in a sensitive manner to *ensure that the client has an understanding of how the deceased will be cared for.*[36]

Box 1 includes elements from the FSCSR Code of Practice which combines reference to treatment of the body and securing consent for that treatment. This Code is styled as a series of 'objectives'. The objectives include seeking to understand client preferences with regard to first offices, secured *at the earliest opportunity*. First offices are always carried out unless the funeral director is otherwise instructed by the client, and no invasive procedure is

[29] SAIF, 7.5.
[30] Scottish Government, *Code of Practice*, 10.
[31] Training manual #1, 90.
[32] Scottish Government, *Code of Practice*, 10.
[33] SAIF, *Code of Practice*, 1.4, 4.2, 6.2.2
[34] NAFD, *Code of Practice*, O(1.4).
[35] Scottish Government, *Code of Guidance*, 6.
[36] Scottish Government, *Code of Guidance*, 9.

to be carried out *without first obtaining your client's informed consent*. These objectives create a link between information, consent and treatment but still include a presumption that families must actively withdraw consent for first offices. In addition, there remains a degree of opacity. O(3.11) indicates that no invasive procedure should be carried out without first obtaining informed consent. 'Invasive procedure' is defined by the FSCRC as *Any care procedure that involves the breaking of skin or the opening of bodily cavities.*[37] The presumption follows, therefore, that where first offices include any invasive element, informed consent must be secured.

Box 1.1: Selected objectives from the Funeral Services Consumer Standards Review Code of Practice

O(3.9) You seek to understand your clients' preference in relation to first offices at the earliest opportunity;

O(3.10) Unless otherwise instructed by your client, first offices are always carried out on all deceased persons entrusted to your care, unless there is a good reason for not doing so;

O(3.11) Subject to O(3.10) and O(3.12), you do not perform any invasive procedure on a deceased person without first obtaining your client's informed consent;

O(3.12) In some exceptional circumstances it may be necessary to perform an emergency invasive procedure with the intent of preserving the deceased person. In the event that there is insufficient time to seek the consent of your client in the advance of any invasive procedure, a clear record of the circumstances and procedure carried out must be kept and made available to inspectors on request.

http://www.fscsr.co.uk/fscsr-code-of-practice-guidance/#1570553228288-ddd5b345-7511

There is variable attention paid to the way that funeral directors should approach discussion of treatment related to the body specifically. Given that this subject is highly sensitive, the guidance around this area is remarkably opaque. In principle, families should be aware of the funeral director processes which fall under the general heading of 'hygienic preparation' and actively consent to those treatments which should not take place until that consent is secured. The draft Scottish Code of Practice, reflected in the NAFD code, requires that first offices always be undertaken, and the tenor of its guidance points towards the family actively 'opting out' of this procedure which otherwise would be delivered as standard despite the family being unaware of what this procedure entails. The SAIF code makes no reference to discussion of the issue.

The tenor of most manuals emphasises discussion of body treatments only in so far as it relates to cosmetic appearance, for example, in asking the family about their preferences with regard to hair, shaving and dress. One manual is rather more detailed and indicates

[37] http://www.fscsr.co.uk/fscsr-code-of-practice-guidance/#glossary

that the funeral director should *openly discuss[…] the treatment of the body entrusted to his/ her care with the family*.[38] Where a family decides to opt out of first offices, the funeral director *needs to ensure the family is made aware of the potential consequences*.[39] Much of the discussion in this manual tends to focus on the ways in which it might be possible to persuade a family that the body should be embalmed. Indeed, a number of pages in the manual provide information on how to present the advantages of embalming to the client. The manual indicates, as a training objective, that the funeral director should be able to describe fully the process of embalming *and where it may offer advantages to the bereaved relatives.*[40]

Industry documents hint at the need to support informed choice but there is a lack of clarity about securing informed consent and the point at which choices are presented and consent secured. Guidance in the codes of conduct is not necessarily helpful in indicating when a discussion about care procedures should take place and what exactly should be discussed. The funeral director survey demonstrated variation in practice. The respondents were asked 'Specifically, regarding care of the body, do you discuss with the family how you will care for the body?'. Around a fifth of respondents said that they provided full details; and a further third indicated that they discussed all aspects but with little detail. A further third discussed some aspects of care only, and just under ten per cent indicated that they had no discussion at all.

Where funeral directors had discussed personal care with the family, they were asked about the point at which discussion took place. The open text box indicates that policy was very much decided by the family involved. Funeral directors were often willing to discuss treatments when asked by the family, and were guided by their own instincts about the stage at which the discussion would be appropriate. Fourteen per cent of respondents indicated that they had some discussion at first contact, although some respondents said that this was something they would be unwilling to talk about on the telephone. Eighteen per cent had discussion on collection of the body. The majority – 80 per cent – indicated that discussion took place during the meeting to arrange the funeral: open text responses indicated that it was more appropriate to have this discussion face to face. However, it is likely that – by this juncture – first office will already have taken place.

Respondents were asked specifically about body treatments they undertook on the last case that was admitted to their service 'without having discussed this with the family first'. The question gave a list of possible actions and an open text box was provided. Box1 lists the possible actions and in brackets the number of respondents who had taken that action without discussion with the family.

[38] Training manual #3, 75ff.
[39] Training manual #1, 80.
[40] Training manual #3, 11.

Box 1: Which of these procedures did you carry out *without* having discussed this with the family first?
[Number in brackets indicates the number of respondents undertaking this procedure]

- Washing [119]
- Dressing [48]
- Hair washing / styling [51]
- Make up with person's own make-up [10]
- Make up using branch make up [29]
- Closing mouth and eyes using non-invasive methods (i.e. positioning only) [160]
- Closing mouth and eyes using glue, or other invasive methods [92]
- Management of blisters and skin leakage [170]
- Managing purging using packing or absorbing granules [170]
- Embalming [8]
- Other (please specify)

Respondents were also able to give open text comment. Some indicated that they would do nothing without express permission of the next of kin, and were committed to full transparency. Others were more likely to be of the view that the actions they took would be expected by the family: *I wouldn't expect to need permission to do these things*. Another respondent was of the view that *Many of these procedures would be upsetting and unnecessary to discuss with a grieving family. If asked we would be happy to disclose and ask. Families trust us with their loved one and are happy for us to do what we need.* There was a sense in which the end objective justified the means: *These types of procedures are not nice for a family to think about, the end result is it is our job to present their loved one in the most dignified and peaceful condition possible.*

Family involvement in body treatment

The industry literature gives very limited indication of the possible involvement of the family in elements of care of the body, and no guidance is given on the ways in which funeral directors might work with family members who may want to be involved in any aspect of washing, dressing and present the body. One manual states that *a member of the family will often assist with the styling of the hair.*[41] No mention is made of how best to introduce the option of family involvement in care for and dressing the body, or indeed how – practically – to involve the family in these activities.

The survey of funeral directors indicates that some respondents welcomed family involvement in body care and others were resistant. Table 1.1 indicates the view of respondents to family involvements in elements of care listed in Box 1. The table indicates that a minority of respondents – eighteen per cent – did not think it was appropriate for

[41] Training manual #3, 8.

family members to be involved in any aspect of care of the body. Just over a quarter of respondents indicated that they would not offer this option but would involve the family if it was specifically requested. Just over half the respondents – 52 per cent – offered this option to families and/or routinely completed care activities with the family present/involved. A small proportion indicated that they would accommodate cultural or religious practices including family involvement.

The variation in responses indicates that it is not entirely likely that a family will be given the option of any degree of involvement in family care, unless they make a specific request from the outset.

Table 1.1 What is your view on family members being involved in any of this care? [Indicated in Box 1]

	Number	Percentage
We do not discuss this and I do not feel it is appropriate	44	16
We offer it but families rarely choose to get involved	73	27
We offer it and families sometimes choose to get involved	51	19
We routinely complete personal care activities with family members present/included	15	6
Accommodates cultural or religious practices‡	10	4
We do not offer it but will accommodate if specifically requested by the family‡	72	26
No demand	3	1
	268	99*

*May not total 100 due to rounding.
‡ These categories were post-coded from open text responses.

Conclusion

This section has reviewed care of the body from the perspective of the industry. There is no obligation to undertake any training in order to operate as a funeral director. In England – unlike Scotland – there is only voluntary adherence to industry codes of guidance. This section indicates that these codes of guidance are remarkably variable in intent, tone and emphasis as is the industry-provided training. Industry documentation indicates adherence to the principle of transparency, but there is a great deal of ambivalence around the degree to which transparency relates to care of the body specifically. Strong guidance in some elements of the industry literature relate to ways in which it might be possible to persuade clients to opt for embalming. However, little guidance is given around: how it might be possible to explain other procedures particularly around first offices and preparing the body

for presentation; the point at which these procedures should be discussed; and means by which consent should be sought. Responses from the funeral director survey indicate wide variation in practice and problems with identifying boundaries between elements of practice including when consent should be sought, and for what kinds of intervention. In addition, although family visits to the funeral director premises were routine, families were not always offered the option of being involved in care of the body unless they proactively requested that involvement. As the next section demonstrates, ambivalence was also in evidence from the point of view of people who had arranged a funeral.

Part Two: The experiences of people who have arranged a funeral

Introduction

This part of the report considers care of the body from the perspective of individuals who have had experience in arranging a funeral. The discussion here expands on findings from an earlier study which sought to understand the parts of the funeral deemed to be the most important.[42] There were five aspects or elements that were deemed to be particularly important, and these included the right level of contact with the body of the person who died. This part of the report relates findings from 30 further interviews that specifically focussed on care of the body. This section will address three of the main research questions:

- To what degree were families involved in decisions about what happens with the body in the care of a funeral director?
- What level of physical interaction with the body did the funeral director support or facilitate?
- How was the FD's treatment of the body judged by respondents?

Essential contexts

It was not possible to generalise across all respondents. To make sense of what happened with a particular body and the respondent's attitude towards that, four contextual factors have to be taken into account and these factors have framed the analysis. First, events and attitudes could be dictated by formal religious belief. Second, an individual's views on care of the body were largely determined by their attitude towards dead bodies in general. Third, decisions made about care of the body reflected the broader trajectory of events surrounding the death including the mode of the death itself and the hours immediately afterwards. Finally, coroner involvement could disrupt the post-mortem trajectory from death to funeral service and reduce the choices available with regard to access to the body and decisions made about care.

Religious requirements

Particular modes of care of the body can be dictated by formal religious tenets. The survey was not able to sample purposively and to ensure representation across a broad spectrum of beliefs. As can be seen in Appendix 1, the largest group of respondents (12) indicated that they had no faith or were agnostic. People who declared themselves to be Christian made the second largest group; of these, one was Roman Catholic. Christian theology does not demand any particular treatment of the body. In Islam, ritual washing and shrouding of the body prior to burial is an essential feature of funeral, but no Muslims were included in this set of respondents. One respondent was Jain and used an Indian funeral director, and to some degree that faith dictated her decisions around treatment of her mother's body.

[42] https://eprints.whiterose.ac.uk/162914/1/FINAL_REPORT_Funeral_Experts_by_Experience.pdf

Two of the respondents were Jewish. In both these cases, the respondent contacted their rabbi immediately after the death, and he made arrangements with a Jewish funeral director. The respondents were not involved at all in any decisions relating to care, because they already knew what would happen. One of these respondents, in talking about her mother, said: 'I knew that when she was taken there would be a ritual, the body would be washed, cleansed and then wrapped in a shroud rather like just a simple sheet, and because there wouldn't be like a viewing of the body, that's not done, so I knew that these practices were would be in place' [COTB23]

Attitudes towards dead bodies

The purpose of the research project was made clear from the outset, and it might be expected that respondents would be more likely to include individuals who felt comfortable talking about the dead bodies. In actuality, the respondents demonstrated a broad range of attitudes which underpinned how they talked about the funeral director's care of the body and their own wishes with regard to contact with that body.

The interview schedule did not ask people any direct questions about what they thought about dead bodies in general. However, in responding to questions more generally some people clearly regarded the dead body *as* the person who died, with a degree of continued but largely undefined sentience and capable of deriving comfort from interaction. Around a third of respondents showed a strong attachment to the body. For example, one woman's father had died in his 80s after a long period with dementia: he had gone into hospital with a chest infection, and slipped into a coma. Her view was that his body had been through a great deal, and after death needed 'rest':

> 'I kind of wanted him to be at rest like as quickly as possible, that felt really important because he'd had such a struggle, you know the last year or so and I just felt like it was the right thing that he got to be at peace and just got to be kind of like safe' [COTB15].

She visited her father every day at the funeral director's premises: 'it's the most important thing to us to care for him'. For this group, the person who dies only gradually 'becomes dead' over a period of time which might extend well beyond the funeral service.

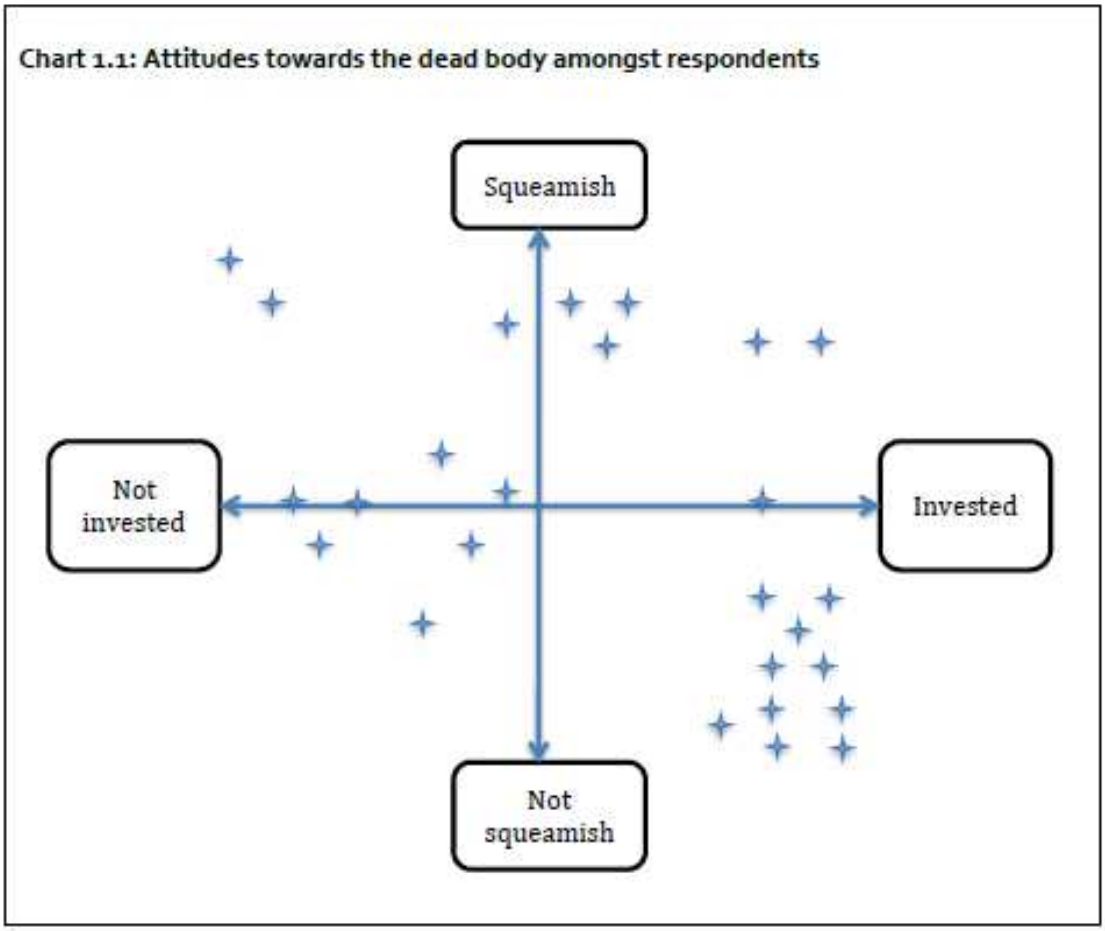
In direct contrast, other people saw no significance in the body at all: they regarded it as a shell which does not retain any identity or sentience and which carries little emotional or spiritual meaning. The moment of death was a rather less fluid and more fixed event. These people clearly believed that, after death, the person who died experiences no benefit from further physical interaction. In one man's view: 'this was a body, that had, past tense, been my father but in many respects of course was no longer' [COTB13]. Similarly, a wife talking about her husband commented: 'I think we respected his soul rather than his actual body. Once he'd gone, his body wasn't really as important as everything else about him' [COTB14]. One daughter said that, after her father died, her priority was supporting her mother: 'it was pretty much about "well dad's gone now and mam is still alive" and he's, he's ok, cause we had been with him right till the end' [COTB27].

The degree of emotional investment in the body was tempered by the extent to which people were squeamish. Here, it should be stressed that this report offers no value judgement on people's personal discomfort as it relates to the dead body. Rather, the intention has simply been to log how people responded to questions on care of the body. Respondents were not asked any direct questions whether or not they were disgusted or distressed by the sight of dead bodies more generally. However, their response to some of the interview questions was a strong indication. For example, respondents could react strongly against relatively unchallenging questions about contact with the body including whether they had wanted to view the body at the funeral director's premises. An elderly man who discussed the death of his wife said that he did not like 'the whole thought of funeral homes' and the thinking about body care was 'an area about which I've always been squeamish' [COTB16].[43] In contrast, other respondents were clearly interested in the more challenging questions about invasive procedures, and gave their opinion quite frankly about techniques such as gluing or sewing eyelids and stitching the mouth closed.

Taking these two elements together, it was possible to place respondents on a chart (see Chart 1): people were more or less invested in the identity and comfort of the body and at the same time more or less squeamish with regard to interaction with that body. Some respondents were very emotionally invested in the body and not at all squeamish about physically handling and manipulating the body for example in washing and/or dressing. Being squeamish was in itself not a reason why people did not invest emotionally in the body: some people could be very squeamish and still strongly invested. There were instances of people who had a strong emotional attachment but who had no desire to see or touch the body itself and might prefer all interactions to be 'closed coffin'. For example, a woman whose sister had died said that she visited the funeral director: 'I don't think it entered my head it wouldn't be closed' [COTB1].

Some respondents sat in a fairly neutral position, in regarding the body without emotion, but seeking to afford some level of respect and being fairly pragmatic for example in tolerating discussion of invasive care but not wanting to dwell on it. This was certainly the case with one respondent who was also a nurse and had her own experiences of performing last offices. She noted that people might have 'very strong feelings about it, and I don't' [COTB5].

[43] Note that interviews were conducted with due sensitivity: where respondents were clearly uncomfortable, more challenging questions about invasive care were omitted.



The death bed and post-mortem trajectory

Funeral Experts by Experience recognised that, following a death, engagement with the deceased follows a trajectory or pathway. The post-mortem interval includes four periods when it is possible for family to have contact with the deceased: in the moments immediately following the death; in the hours and sometimes days after the death, before the body was transferred to the funeral director premises; formal visits at the funeral director premises and in instances where the body was brought back home prior to the funeral service. This report focuses on the points in that trajectory when the funeral director was directly involved. However, it is important to understand the broader context, since there were occasions when the mode of death altered the range of options and had a strong impact on the significance of funeral director care of the body.

Around two thirds of respondents were in attendance at the death bed, irrespective of whether the person died in hospital, hospice, a care home or at home. The death was expected and in some cases protracted with family members maintaining a vigil lasting for days. Being in attendance meant that the family spent time with the body immediately after death and before the funeral director was called. This was clearly an important time for many respondents, when they could observe the body 'becoming dead': one woman spent eight hours with her father following his death from renal failure, and described how his body became gradually became cold until all she could feel was a little warmth behind his back [COTB9]. Another respondent was also with her mother when she died in hospital.

Staff left her stay in the room for 'a long, long time', and 'very quickly I could see the difference between my mum that was alive and the dead mum' [COTB6]. This was also, simply, quiet time. One respondent talked about her father, who died of pneumonia in a care home and increasingly had trouble breathing. After his death she said, 'we could stay there as long as we wanted, it wasn't worrying us that he was dead, it was nice to spend time, and actually some of the staff came and saw him and said goodbye to him' [COTB27].

For some respondents, this period of attendance at the deathbed was rather more emotionally significant than seeing the body at the funeral director's premises. This was the time when respondents 'said goodbye'. One woman talked about her mother's death at home, which had taken place with all the family there. She and her sister did visit the funeral director, but only to support their other family members: 'she and I had sort of said our goodbyes on the Saturday when mum had died when she was at home, that's when she looked more like mum' [COTB25]. A wife talked in detail about the death of her husband: she felt she had lost years him years earlier, since he had been suffering from dementia and was no longer the husband she knew. It had been 'a hard few years'. Over time, he developed multiple medical conditions and the family attended him at hospital: 'we had lots of time to spend with him, so my son and my daughter live about an hour away and they were able to visit frequently. I went in everyday and was with him a lot, and we had plenty of time to kind of say goodbye' [COTB14]. She had no desire to see his body again after he died.

In other cases, the family arranged for the coffin to be delivered home the night before the funeral, and this might be regarded as the more significant time which precluded a funeral director visit. One of the respondents said that she had been with her father when he died: 'we had been with him in the hospital, which was like three days basically whilst he was in a coma, and then we knew we were going to have him laid out [at home], there wasn't a point when we particularly wanted to go, we didn't feel like we needed to' [COTB30].

Mode of death and coroner involvement

A final important contextual factor framing decisions around care of the body was the mode of death and any necessary investigation into that death. Coroner involvement signals a death out of the ordinary, which disrupts and lengthens movement through the post-mortem interval. Eleven of the deaths took place in circumstances that required investigation. These included sudden deaths from strokes or heart attacks or the unexpectedly rapid deterioration of individuals who were known to be ill. In one instance, the death was a suicide: one woman's elderly mother had cancer and decided to end her life before she became further incapacitated.

Two of the respondents talked about deaths that were deemed to be particularly problematic. One woman talked about the death of her ex-partner, who had died suddenly at home. She had taken their children to the hospital, by which time he had been transferred to the hospital morgue. This was the last time they saw him before the funeral: a cause of death was not immediately evident, and there had been a protracted investigation. She had been advised against seeing him again once the coroner service released his body: she was told that 'his body would have decomposed quite a bit and the colour, the colour of his face and his body, and that it wouldn't be, it wouldn't be good for

the girls to see him like that, or anybody else for that matter' [COTB26]. Another woman saw her son at the morgue and then again later at the funeral director's premises. Her son had had cystic fibrosis and had called 999 because he had trouble breathing. He called his mother at the same time, and she heard him die over the telephone. She rushed to his home but the police blocked her access to the room where her son was: 'they were scared I was going to run up the stairs, which was a fair chance I would, but it was words like you might contaminate the evidence, it was like what evidence, you know, and I just, I just needed to see him and touch him and be his mum'. His death was regarded as being 'unexplained' despite his having a pre-existing condition, and his house was 'treated like a crime scene, we all felt like criminals'. She did not see her son's body until two days after his death, when she was asked to formally identify him at the police morgue. It was a harrowing experience for her: 'he didn't look pretty, put it that way, there were no marks or anything, but his mouth was open his tongue was half hanging out where…It was awful, a terrible terrible thing, and it just, just I hate the word protocol now as I heard it so often from the police' [COTB20].

The mode of death and coroner involvement introduced a different dynamic to decisions around whether the body should be embalmed. A woman whose mother had been found dead at home was told by the funeral director that 'it was probably best to have her embalmed because she had waited so long for the post-mortem', although she now felt that she had been rushed into that decision [COTB2]. Another daughter, whose elderly mother committed suicide, said that her mother's body was not released from the coroner service for six weeks. The funeral director told her that the body would need to be embalmed if a viewing was to take place. In her view, the matter was 'taken out of our hands' and she felt very distant from that decision [COTB26].

Family involvement in decisions relating to care of the body

All the preceding contextual information needs to be taken into account in assessing the degree to which families were involved in decisions about what happens with the body in the care of the funeral director. Decision-making in this area was a remarkably complex interaction: effective communication depended very much on the ability of the funeral director to accommodate both an individual's attitude towards the body in terms of attachment and squeamishness, and the ways in which the manner of death might preclude some options. Respondent experiences indicated that funeral directors could be highly skilled and supportive in guiding them through decisions in a sensitive fashion. However, there were also instances where the funeral director excluded families from effective decision-making by a failure to discuss possible options. In extremis, some funeral directors made decisions on care which did not include the family or which contravened family wishes.

In the context of the interviews, 'care of the body' covered three principal activities where it might be expected that the family would make active decisions on how they would want the funeral director to proceed. These were: whether the body would be embalmed; possible family involvement in washing the body, and fixing hair and make-up; and on

practices to set the features which might include invasive suturing and/or the use of heavy make-up to ameliorate damage to or deterioration of facial features.

The level of detail in respondents' narratives with regard decision-making around these three specific areas was highly variable, and reflected both their degree of emotional investment in the body and their willingness to talk about things they might personally find distasteful. These narratives sometimes make it difficult to judge where a funeral director might not have opened up choices and options for the respondent to consider, or if the respondent themselves quickly shut that conversation down. One respondent found her funeral director unforthcoming with regard to details: 'I think they were being, trying to be tactful even though we did want all that information [COTB22]'. In another case, it seems both the funeral director and the respondent themselves sidestepped discussion of care options: 'No he never said anything. Nothing. He didn't volunteer anything and, to be fair, I didn't ask because I didn't want to know' [COTB7]. However, in other cases it was clear that the funeral director had indeed forwarded options but the respondent had not been interested because the body was simply not important to them: 'we were both absolutely adamant that we didn't want to see him and therefore we didn't want anything done to him that was invasive mainly because we didn't see the point' [COTB14].

Four main themes emerged from analysis of narratives around decision-making: instances where families stepped away, and – conversely – instances where they were more actively involved, a failure of communication between the funeral director and the family, and ambivalent feelings about the decisions that were made.

Stepping away

There were some respondents who were very happy *not* discuss how the body would be cared for, and who made a more or less conscious decision to step away from receiving information about options. In these cases, control of the body was relinquished to the funeral director and the respondent entered into no further discussion of the body until the funeral service. One man, who talked about his wife, said 'But, how they actually managed [his wife's name] at their parlour, I still to this day… I could've asked for more detail but I didn't. I suppose it's an area about which I've always been squeamish anyway, so I didn't ask' [COTB16]. Another man, also talking about his wife, was similarly resistant to having more information: 'for me personally I didn't really want to know. I suppose in a morbid kind of thing. I took the view that whatever you would have to do you would do' [COTB3]. A woman discussing her father also felt that more information about care was irrelevant to her: 'I don't think I was too bothered about it I know it sounds awful but I think I knew that they were gonna dress him, I know they were gonna make sure that he looked presentable for us so, I think in my mind that's all I really cared about' [COTB19]. In this regard, there was simply a trust that the funeral director would do the right thing. Another woman who did not see the body from the time of death until the day of the funeral also had no discussion with the funeral director about care: 'my confidence and my comfort was in the people, and so I kind of just knew straight away they would look after him' [COTB27].

Active decision-making

A larger group of respondents were more actively involved in decision-making. For some, the level of information they received from the funeral director met their needs, and enabled them to make choices. Respondents themselves acknowledged that funeral

directors were faced with a difficult task, in measuring how much information would be palatable to people whilst signalling that further information was available. One woman in her sixties, arranging the funeral of her sister, had discussed some elements of personal care with the funeral director but clearly had not wanted too much information:

> I didn't feel that they were, like, giving me loads and loads of detail, but I feel that if I'd asked, they'd have given me more, so that felt okay, I can see that that's quite, you know…because some people will want to know and some people won't and so I guess what I'd want is to feel that I could ask anything that I wanted, and they did say "Is there anything else you want to know" and so on [COTB12].

One area where people often did express a clear preference was in whether or not the body would be embalmed. There were a number of respondents who had made their wishes on this matter known to the funeral director very quickly. People were often guided by their own experience in this matter. One woman's mother had died abroad, and it had been a requirement that the body be embalmed prior to repatriation. 'Her presentation wasn't good, it wasn't a nice thing', she said, and for this reason expressly ruled this out for her father [COTB15].

Other respondents mentioned that they had been unfamiliar with the process, and described the way in which the funeral director explained it to them. Often, the response to the procedure tended was negative: one woman found it hard to understand, and pushed the information away very quickly:

> I don't think I wanted… I knew there was processes to… Possibly like chemicals. No, I don't wanna know that level of detail. The important thing for me was to think about the human bit that I could do for them. I understand clothing! […] It was just important for me to focus on the human element and the clothes they would've wanted. That felt like the focus. I didn't need to know what was happening behind the scenes [COTB6]

Another woman said that embalming had been suggested 'in the context of keeping Dad intact and more like himself kind of thing'. It was a 'clinical conversation' and in the end something she did not want to happen [COTB9].

If people could be quite clear about their wishes for embalming, they could also be very assertive when they wanted to be involved in washing and dressing. This was the case with two of the respondents, who clearly anticipated that this option would be open to them. One woman had been adamant about this preference, since her mother had said that she wanted to look presentable when she died, and her daughter had promised that no-one else would touch her body:

> But I made it clear to them that I wanted to make sure that I was the one that got my mum dressed and I wanted to do her hair and I wanted to do her makeup, things like that, I didn't want anybody else doing that, and they was they was absolutely fantastic about it they said I could do what I wanted [COTB8].

Another woman had been similarly adamant that she wanted to prepare her father's body, and had a series of open conversations with the funeral director on the matter. Her father had died in his late 80s, and it was uncertain how quickly the body might deteriorate. The funeral director advised his daughter:

> she said that they couldn't necessarily say for definite how somebody may look because it depended on various things, like you know, what condition their skin was in beforehand, so she talked thought all that with me and she said that she'd have a look at him first then sort of tell me what she thought, then I could decide if I wanted to have a look at him and, yeah, so, and then I did, she looked at him and said "he looks fine actually" and he did, he looked fine really [COTB15].

In both cases, the funeral director directed the respondent through their washing of the body with great sensitivity, feeling their way with the respondent to ensure that they were happy. The woman described how she applied her mother's make-up and paused just before she began to blow-dry her hair. At this point,

> she asked me again did I did I want to do it on my own and I said no its fine if you wanted to stay in and she said it was completely up to myself if I wanted to be on my own or she wanted me there. I was a little… I wasn't scared [chuckles] it's just that I hadn't done it before I just needed her with me really I think [COTB8].

The other respondent felt similarly supported when she opted to wash her father's body:' They were very…that's partly why I felt comfortable about working with them (ie the FD), I suppose. They were just like…I remember she just kept saying to me "Well, it's your dad" and that just felt really nice' [COTB15]. In both instances the respondents had looked for comfort in the perceived benefit that this personal attention brought to the person who died, and had been fully supported in their decision-making.

Unsurprisingly, the respondents who were less squeamish were more likely to be active in decision-making around procedures which set the facial features. This was an issue which came up when the person died with an open mouth or eyes. Some respondents were told that more invasive steps would have to be taken in order to establish a more settled expression. A woman whose adult son had died suddenly recalled his expression when she saw his body in the mortuary and had discussed the funeral director's preparation of the face. As with all other respondents taking an active role in decision-making on invasive procedures, she was pragmatic:

> I don't like them, but I understand why they have to be done, I don't know if there is an alternative, I know that you newly die, if you wrap up a towel you can force the mouth closed, but he been laying with the tube down his throat because the paramedics don't take off all the equipment, they've got to leave it for the police, that's why his tongue was in a funny position [COTB20]

Where respondents had decided not to agree to such procedures, they often reflected back on that decision in discussing how the body looked during formal viewing. A face with open eyes and mouth was regarded as being too disconcerting. The woman who had attended to

her mother's body personally said that she had agreed to her funeral director stitching the mouth after her first formal visit:

> She was, when she died she died with her mouth open and no teeth in, and when we went to, when I first went to see her I said to her "oh gosh she's still got her mouth open" and she said "oh no we can close it for you" so she did, she did and I couldn't put the teeth in so she put her teeth in and she did close her mouth, but she did explain that they might have to put a little stitch in her mouth to help to keep it closed and I said that's fine but I said I just don't like looking in my mum [COTB8]

The woman who had washed her father had also not opted for this procedure. She found his open-mouthed expressed distressing and thought it would have embarrassed her father. In the describing her feelings, she rationalised her opinion on the matter.

> He would have just felt a bit like "Jesus, people are looking at me and my mouth's open". I, but then it was only me and my husband, so think he'd be like, "Oh, so that's alright", like, so, it wasn't really important for me as in, like, because that's who he was, that's just real. So he didn't look, he looked a little bit shocked I suppose. Not shocked, no he looked kind of, he looked like he was sleeping actually really, he looked like he was sleeping. And actually, when he used to sleep, he used to sleep quite a lot with his mouth open [COTB15].

In a couple of instances the decision was taken to rectify the appearance of the face after the respondent had visited and viewed the body. The family arranging for the repatriation of their father's body had been quite adamant from the outset that they wanted the presentation to accord with their wishes, since the body would be on display during the funeral service. They had been clear about the kind of make-up that should be used. However, on visiting the funeral director's premises they were not happy: 'the face was really oddly set and we told him, we were very frank, that looks weird and not how a normal human being ever looks, I think they tried to set it in a smile but it ended up being an odd stretched thing, so they tried to fix it' [COTB22].

Failures to communicate and exclusion from decision-making

In some instances there had been a failure in communication between the funeral director and the respondent, as the meaning of particular procedures was not made clear. One respondent had decided against make-up for her father, and in her mind had envisaged the funeral director applying lipstick. She admitted that this had not been an informed decision, and had been shocked to see his face at a later visit: his face was discoloured and he looked 'super dead', which she had not felt prepared for [COTB21]. There were cases where respondents had been simply led to making a decision without that option being explained. Again, embalming was a point of contention: 'I didn't know I had a choice about the embalming. It's kind of sort of sold to you' [COTB2].

Other respondents had made more informed decisions, but found that their wishes had been contravened. For example, one woman's mother had died following a fall at home, which had damaged her face. The funeral director asked if the respondent had wanted them to rectify this damage in presenting the body, but the decision was taken against that option: 'I said I don't want you to do anything. I don't to put any chemicals in her body, I

don't want you to do anything like that'. However, when she visited her mother later, the funeral director had indeed remodelled the face:

> they said "oh you know they've done a good job of the face" so I said "oh you have actually played around with the body then", they said "yes we've made her look nice for you" and I thought well, it's too late to sort of make a complaint but I had asked them not to do it [...] and I know they were only doing it for our benefit you know it was it wasn't done with any malice it just wasn't our wishes but, so yeah just, some things just have to... well I let go of it a long time ago, yeah [COTB10].

There were also cases where respondents only realised later that something had not been offered. Some women regretted not being asked about whether they might want to wash or dress the body. One respondent had cared for her baby in this way, and her grandmother. When her mother died, the body had been taken from the hospital and the funeral director had simply excluded her from any decisions made about care [COTB2]. Another woman talked about the death of her father which had happened some twenty years previously. She still regretted her lack of active involvement:

> there were no choices. They did all of the critical side of that. It was never on offer. Actually, somebody like me, I would have been quite straightforward and easy helping them to do that. There is something about, they used to call it "last offices" when I was a student nurse. There's something about, it's the last thing you do on somebody. I think it's really important and special [COTB5].

Ambivalence

One theme running through many of the interviews was a degree of ambivalence: respondents were not certain about being more actively involved in decisions, since this would mean being party to more information which might not be welcome. In the words of one respondent, 'I don't feel as though choices were explored but I'm not sure I really wanted to explore the choices' [COTB16]. Respondents could regret the conversations that weren't engaged in: 'I probably would have liked a bit more, yeah, bit of a discussion about how they maintain the body you know until time of the funeral, don't think we were given that so that might've been helpful' [COTB18]. For information to remain unknown could be equally distressing: 'talking about it and that makes it more real, and it is almost easier to accept actually sometimes if you do talk about it, instead of it being this unknown thing that is happening to this body, that you don't even talk about it, maybe that's worse' [COTB30].

Attending to logistics

A core function of the funeral director is logistical: the collection and storage of the body until the funeral service. Attending to these logistical elements sets a tone which gives reassurances to families with regard to care and respect. One marked theme which emerges from the discussion of logistics is the degree to which the majority of respondents effected a mental separation from images they thought they would find distressing.

Collecting the body

In around half the cases discussed by respondents, death took place in a non-medical setting and in circumstances where they were present when the funeral director arrived to collect the body. Few respondents wanted to be present when the funeral director moved the body into the carrier. There was a wry acknowledgement that collection presented a particular challenge to the funeral director: to act efficiently and respectfully and in a way that minimize stress for everyone present. The funeral director was often very clear with respondents that they might not want to see their handling of the body; many respondents agreed. One woman said that she had been distressed even by the fact that the funeral directors mentioned a body bag:

> that just seemed a bit kind of like I don't know how else they could have said that to me but that just seemed you know because when you say that then you've immediately got that kind of visual of you know you're imagining you know the body bag thing [COTB2].

People moved to other parts of the house; one woman moved so that even the noise would not be audible. Her partner had been a big man, and she knew the funeral directors would find it difficult to move him. There was a sense in which viewing this process would create unwelcome images: one woman, who did not visit at the funeral directors', wanted the last view of her son to be peaceful: 'I assumed that he would be in a bag, I didn't want to see that, and yeah, we wanted our last memories to be how he was, how he was laying there' [COTB24]. One man summed up a particular briskness in the funeral director's approach, and also his relief at not seeing the collection. His father had died in the night, and told the funeral director they could wait until first thing in the morning to collect the body:

> The funeral director turned up, 8.30 as I say, it was, it was clearly a process. "Hi, I've got something to collect, where is he?" … So he's then brought his pal in, they went up to the bedroom to see where my father was and they then carried him away, now I didn't see him put into a bag, I didn't see him carried down the stairs, I didn't see him put on the trolley, I didn't see the hearse go […] it was very efficient, you know, and I don't doubt for one moment that they, that they were good but I just didn't need to see this.

He had seen this process with his father-in-law, and described it as 'somewhat agricultural' [COTB13].

One or two respondents choose to stay in the room as the funeral director moved the body. These respondents were more likely to have a strong emotional investment in the body and be less squeamish about these matters. They said they found it comforting that the funeral director had continued to talk to the person who had died, and to use their name. A woman who had a very close attachment to her mother and had washed her body said that she had opted to stay despite being warned by the funeral director that the process would be messy since the body had leaked a good deal of fluid. She watched them clean her mother up and place her in a bag:

> When they're picking her up you know they very gentle with, I was scared when they came in to pick her up I just thought they were just throw her on a trolley and the they were talking to my mum and I thought that was really, really nice cause I thought well they're talking to my mum as if she's still there, they was explaining look we're gonna be, we're gonna be putting you on this trolley [person that died's name] and, and that and that was really important to me and it gave me the reassurance that they were gonna carry on treating her like that when we weren't there so, that was a massive thing to all of us.[...] I'm glad I stayed because I didn't want it to be any other way [COTB8].

Storage at the funeral director's premises

Respondents were not very forthcoming in discussing how they thought the funeral director might store the body. There was a general presumption that the funeral director would be using some kind of 'fridge or freezer or whatever' [COTB10] although one respondent said that the funeral director used a cold room. Respondents often said that they really did not want to think about it: 'No. I suppose... for me personally I didn't really want to know. I suppose in a morbid kind of thing. I took the view that whatever you would have to do you would do. I didn't really feel that I needed to know what you were doing. I didn't really feel I need to know what it would be like' [COTB3].

Where people attempted to describe how they felt it would be, images were generally negative: 'it's kind of a not nice place you wanna go to right [laughs]? It's all stainless steel and that's how you imagine it. I didn't need to be there or see that' [COTB9]. Indeed, people could find the image distressing: 'I think that's what people, people perceive, to happen when you die that you know they go in a drawer and it's effectively a fridge and, and I tried not to think about it too much cause I think if you do it, it can freak you out'. [COTB18]. One woman said that she did not want her image of 'American crime dramas' to be confirmed: 'if it had been not like that and more personal then I would have gladly known that, but I didn't want to risk the confirmation of the impersonal nature of it, if you see, if that makes sense' [COTB24].

Visiting at the funeral director premises

The interviews aimed to establish what level of physical interaction with the body was supported or facilitated by the funeral director, and for many people this took place during a visit or viewing. Distinguishing these two actions is appropriate: some people simply wanted to see the person who had died; others wanted to kiss, touch and, hold hands. Nine of the respondents did not visit for various reasons described above, although it was common for these respondents to mention that the funeral director had clearly offered encouragement. A woman whose father died in a care home, and who had wanted no further contact with his body, said that the funeral director did attempt explore the circumstances in which the woman might want to visit. This was also the case with the woman whose young son had died and who also had no desire to see his body: the funeral director 'kept making sure that we didn't want to change our minds and go and see him, which was really good. I think even right up to the day before the funeral, because there was quite a long gap, she was just offering the opportunity if we wanted to' [COTB14].

Arranging to visit

Twenty of the thirty respondents did spent time with the body at the funeral director's premises. *Funeral Experts by Experience* found that this time alone with the person who had died could be highly significant. Here, the focus is on the funeral director's role in preparing people to see the body, providing an appropriate setting, and offering support. All the respondents indicated that the funeral director was happy to make arrangements for visits to take place, and quite prepared for respondents to turn up with little notice. The woman whose adult son had died had waited for some time as a consequence of the coroner's involvement, and had eagerly received the call from the funeral director. When they phoned to say that the coffin had finally arrived she said 'I'm coming now [laughing], they said that's fine, and off I went' [COTB20]. From respondent accounts, funeral directors facilitated single, quite formal, viewings with family members alone or in groups, and also more fluid encounters where respondents repeatedly dropped in. One woman whose husband had died said that she visited her husband nearly every day for an hour or more, but the funeral director was always welcoming: 'It made everything such a beautiful experience. We'd sit down. We'd have a cuppa. We'd have a chat. Then, they'd say "when you're ready you can go in" [COTB11].

Funeral director support in visiting

Some of the respondents who talked about visiting at the funeral directors' mentioned that they had seen a body before, and had some understanding of what to expect. This was not always the case, and some respondents felt rather more prepared than others for what they encountered. The degree of support given by the funeral director was variable. At the most perfunctory level, one respondent said that the funeral director had simply pointed her towards a door, said that she could take as long as she wanted and for her to 'call us if you need anything' [COTB2]. Many respondents, particularly those who were inexperienced or highly apprehensive, said that they had wanted more information and preparation about what visiting entailed exactly, and what they would see. A respondent who was in her teens when her mother died said that she had not felt prepared by the funeral director even at a very basic level:

> I don't think they explained what would happen, do you know what I mean, I think in retrospect, and I'm really aware that like being quite young will have maybe coloured this experience, but because I had never, cause I had never seen a dead body before or anything, like it would have been quite helpful for them to go "so what you do is you will come into, we have these little rooms, and your mum is going to be here and you're gunna have as long as you want, or the slots are like this long" and I just, I needed the obvious things stating, like I needed them to state the obvious, and I think sometimes they sort of assume that I would know maybe [COTB21].

Another woman had been very anxious about the appearance of her mother whose death had been examined by the coroner, and where deterioration had been an issue. She said that she had been greeted with a cup of tea, and the funeral director had a long conversation with her about what her mother looked like: 'I think she did as much as you could do to prepare somebody to walk into that room' [COTB10].

Appropriate settings

The respondents were asked what they remembered about the room in which the visit took place. There were positive comments where rooms were laid out with touches of comfort: not all funeral directors provided chairs, for example. Some rooms had boxes of tissues, flowers, lit candles and music. Respondents evidently wanted to an ambiance that was positive, but where the 'stage management' was not intrusively noticeable. Smell was one particular element that elicited comment, and was something that some respondents worried about: 'it didn't smell, and that was the main thing for me' [COTB8]. One woman had been disconcerted by the smell which she said was 'kind of weird. [I]... don't know, didn't smell particularly nice' [COTB2]. Overpoweringly strong smells of flowers and air fresheners also elicited negative comment.

Respondents mentioned 'beige' and 'neutral' rooms where there was little to say in the way of description. However, there was a good memory for rooms that were poorly presented or so very neutral as to seem clinical or functional. One woman said that the room she visited felt like a neglected office: 'like it's a sort of, it looked more like a room you put boxes with old accounts in' [COTB21]. Another woman, who had gone with her mother to visit their father/husband, said that the room had been so claustrophobic that they had left almost immediately:

> the room was small and I didn't feel comfortable in there and I'm not easily creeped out, it wasn't the first dead body I had seen, but it was just not that very... not nice. "Let's get out of here", and my mum was like "and thank God you said it" coz she was just feeling [laughing] the same thing [COTB22].

Creating the right image

One of the most closely scrutinised roles played by the funeral director is their presentation of the body where families choose to visit. As has been seen, respondent with no emotional attachment to the body or who were overly squeamish generally decided that a visit was not 'for them'. For the remaining respondents, a visit was required to fulfil a number of purposes and might involve multiple returns to the funeral directors' and active on-going dialogue with the person who had died. For many, there was simply a desire to view the body one last time: it was a goodbye, a confirmation of death, a consolation that the person who had died had been cared for and also a check that the body looked 'right' in its final presentation.

To this end, the funeral director had to ensure that the body was presented in a way that respondents deemed satisfactory. 'Satisfactory' covered a relatively narrow spectrum. Some respondents were generally pragmatic, and simply expected to see a dead body. Attempts to improve the appearance of the person who died were not necessarily welcome: 'I almost don't like the idea of making someone look like they are in life, because they're dead. [Small laugh], it's a bit of a sort of paradox really isn't it' [COTB28]. Another respondent, similarly, had wanted to see her sister 'as she was at that moment really', clearly dead [COTB12].

It was more typical for respondents to want a final image which showed the respondent no longer in pain, and at peace. Many had seen the person they loved suffer months or even years of progressive decline, and it was a relief to see their face no longer contorted by illness: 'We wanted to make sure she looked as if there was no pain. No suffering. We just wanted her to be at peace really [COTB2]. Indeed, as might be expected, respondents typically made reference to a natural sleeping expression: 'I think it felt organic. It felt like the face she pulled when she was asleep' [COTB21].

The respondents who were more likely to want to visit were also people who tended to be rather more pragmatic about the possible need for invasive procedures to create the right kind of image. One woman had made arrangements with her mother with respect to their father/husband. She was herself a nurse and so quite familiar with last offices. However, she knew that her mother would have been 'fine with anything you do to make the person look ok as possible' [COTB5]. For this group, the last image was rather more important than how that look was achieved: there were a number of instances where respondents specifically asked for eyes to be closed since it was 'weird' for it to be otherwise [COTB18]; 'I don't like them [ie closure procedures] but I know it has to be done' [COTB20]. Indeed, one respondent said that she had actually expected that the funeral director would glue eyes shut and wire the jaw although in the end neither measure had been necessary.

Poor experiences at the funeral director premises generally reflected the fact that some respondents regarded a dead body that had been 'prepared' by the funeral director as rather less palatable than the body they had left on the deathbed. The presented body was a construct, a 'wax doll' [COTB7] and – in another respondent's view 'just like looking at a Madame Tussaud's version of your dad' [COTB22]. One respondent was hugely distressed by seeing her mother and spying evidence that her mouth had been closed:

> I remember her lips being stitched and being able to see the back of the stitching. […] As soon as I saw my mum, I retreated. I was very, very upset. That came as a surprise. Obviously it hadn't bothered me, viewing the dead body when she was looking like her, but as soon as I'd seen her prepared, or whatever they'd done. It was very, very scary [COTB6].

These instances often reflected circumstances in which a respondent had viewed the body somewhat against their natural inclination. This generally reflected the respondent visiting in dutiful support of other family members.

Family evaluation of funeral director's care of the body

A number of themes emerge from respondents' accounts of funeral director care of the body. The first is ambivalence around information, communication and proactivity. Most respondents lacked the knowledge and even language to engage in informed discussion about what physical care might entail. At that same time, respondents could express a very deep reluctance to become party to that information. Where respondents had strong views which were clearly expressed from the outset, the funeral director generally fulfilled those preferences. However, it was more common for respondents to lack strong preferences

because they were uncertain about how they felt and about how they might articulate their feelings on the matter. A woman making funeral arrangements for her sister had left the funeral director to make the principal decisions but was then ambivalent about how they had set her features:

> maybe her mouth was closed in an artificial way, there was something about (pause) there might've been something about the way it was... it wasn't... but then because she was dead so long, I wasn't expecting normal. Yeah I feel okay about that, I feel okay about them doing what they needed to do. I wouldn't have wanted it to be like altered in any way, and I don't know how much they might've done anything to make it look more, less dead, I mean I don't actually know, I didn't ask [COTB12].

In many accounts there was a great deal of grey area where it would have been appropriate for the funeral director not to have not taken a respondents' reluctance to know at face value and instead offered a tactful lead in guiding the respondent through possible options and outcomes.

Respondents sometimes expressed regret for the choices they had made. One woman had been very unhappy with the funeral director's 'hygienic preparation' of her mother and the invasive face-setting procedures: 'I wish I hadn't had her embalmed and I wish ...I would have had more time to decide about it and I feel like I was sort of driven into it, the closing of the mouth' [COTB2]. Others regretted that they had not been more proactive with regard to involvement in washing and preparation. For example, one woman said that she would have been pleased to have washed her father's hair: the funeral director had not arranged it the way he like it. Respondents had simply needed more time to think.

The second theme related to the degree of support that was expected. As with many aspects of care of the body, respondents acknowledged that funeral directors were often trying to tread a delicate line between being supportive and being intrusive. The woman who had visited as a teenager said that she thought the funeral directors' intent was to give them space, 'and not stand over us, but I do think that having, you sort of want someone who's there if you need them, visibly there if you need them, but not but not sort of (small laugh) not loitering'[COTB21]. Other respondents expressed a similar sentiment: 'I feel I got what I needed. Someone else, in the exact same situation, might say they didn't. It's taking the cues as a funeral director from the family and from what people are saying. Also what their body language is. It's really tricky and difficult' [COTB17]. It was not always regarded as the funeral directors' role to be supportive: 'They weren't inappropriate in anyway but I don't think they would be particular tuned in to how people were feeling. But equally I wouldn't be looking to them for support either' [COTB5].

A third theme was the presumption that funeral directors could be trusted to act respectfully and professionally, and this meant that families did not necessarily have to make active choices. One woman said that her family had decided quite quickly that they did not want to visit: 'we felt and knew that with a long established funeral director that he would be well cared for and you've got to trust the professionals like that and I think it's not something that we wanted to worry about' [COTB14]. In one respondent's view, funeral directing

> it's not a dark art but, it's an art that is for the professionals. It's a bit like heart surgeons: I don't need to how you're doing and why you're doing it. I just know that the output is required and very nice and the right people are doing the right thing. I think that whole insinuation that you're good at what you do and that's what you're there for is enough for anyone. I couldn't imagine anyone wanting to talk through what actually happens with a dead body [COTB6].

The fact that many respondents found it very difficult to dwell on what might happen with the body increased their hope and trust that the funeral director had matters well in hand. Even minor signals and reassurances that the body would be treated with respect were regarded as sufficient warranty that no further information was necessary.

Conclusion

These interviews indicate that substantial complexities that lie around decision-making with regard to care of the body, from the perspective of families. Care of the body is dictated by some essential contexts. Some of these contexts – for example, coroner involvement or religious requirements – are straightforward to negotiate since both define set procedures. Family time spent with the body immediately after death also constitutes an important context. However, a key issue is how the people who are arranging the funeral regard the dead body. This report has indicated that the level of emotional investment in the body and squeamishness together dictate the degree to which there is active engagement with decision-making around care of the body. It was evident that families that had strong views generally had those views respected: funeral directors generally followed the wishes of individuals who had wanted to be involved in body care or who had actively indicated that they did not want the body to be embalmed, or indeed who wanted no involvement at all. However, problems tended to arise where there was ambivalence and uncertainty. These created silences which neither the funeral director nor the family felt willing or able to disturb.

Part 3: Conclusions

Introduction

This final section of the report will draw together major conclusions from the first two sections. There is substantial ambiguity around the delivery of care of the body in industry guidance, reflecting the high level of sensitivity attached to this subject. In qualitative interviews, individuals displayed a wide range of attitudes towards the dead body, including variation in tolerance for information about care. Many people felt they could trust to the professional judgement of their funeral director. However, funeral directing, as an industry, is supported by industry-supplied training but this is in no sense compulsory. People using funeral directing services trusted that their funeral director would do the right thing. In actuality, the 'right thing' is often defined by funeral directors themselves, which leads to wide variation in practices as it relates to care of the body.

This study concludes that 'transparency' is less useful as a guiding principal in this particular context than the aim of securing informed consent. Given the sensitivities of the subject, it is unlikely that many people securing funeral directing services will tolerate fully detailed information about the more intrusive aspects of bodily care. However, this does not preclude the funeral director giving active support to clients to help them make informed decisions. Funeral directors should aim towards securing express consent rather than being satisfied with imputed or presumed consent. To that end, this final section introduces a set of tools that can be used by funeral directors to negotiate the sensitive conversations around decision-making as it relates to care of the body. These tools encourage reflexive practice, and augment the development of funeral directors' emotionally intelligent, people-facing skills.

Ambiguity in the delivery of care of the body

A principal finding from reviewing industry-produced literature and codes of practice is that guidance relating to informing and securing consent from families is ambiguous, and generally rests on family members clearly articulating their preferences without necessarily being prompted. For example, the draft Scottish Code of Practices indicates, under point 15, that *when requested, the funeral director must describe their services for first offices in a way that is sensitive to the client, to ensure that the client has an understanding of how the deceased will be cared for by the funeral director* (own underlining). However, the Code then goes on to indicate, under point 16, that *where it is possible to do so, first offices must take place in every case, unless the client has specifically requested that first offices are not to take place.* Thus, first offices will be performed unless otherwise instructed but information on first offices would only be given to a client if they ask for it. This requires a degree of family proactivity in a highly uncertain area. Respondent interviews indicated that where families had a strong view then they were likely to articulate their preferences at a very early stage in their dealings with the funeral director. However, many were reliant on the funeral

director to guide them through the decisions that needed to be made. Funeral director responses in the quantitative survey indicated a high level of variation in the inclusion of families in decision-making and the degree to which it was thought appropriate for families to be involved in care.

This ambiguity reflects the often acute sensitivities around the subject of the dead body. Qualitative interviews indicated that people have varying degrees of emotional attachment to the body when a person they know has died. At the same time, people are also to some degree squeamish and may have a low tolerance or even revulsion for any conversation that might cause them to reflect on the body's physicality and any manipulation of the body that might be required. Some people may be highly distressed and step back from detailed discussion of care and not arrange to visit the funeral director premises to see the person who has died. Others might 'lean in' to those discussions, want further information and in some cases personally want to be involved in washing and dressing. The interviews indicated that, irrespective of their attitudes towards the dead body, people were clearly dismayed and even upset by actions taken against their wishes.

Funeral director training

In these circumstances, a great deal rests on the professionalism and skill of the funeral director as they interact with the family. The qualitative interviews indicated a mismatch between families' presumption that funeral directing rests on some level of professionalised minimum standard and the actual lack of any statutory requirement that funeral directors be formally trained. The qualitative respondents were generally of the view that, particularly where they had achieved a good rapport with the funeral director, their funeral director would attend to care of the body in an appropriate way: 'My confidence and my comfort was in the people, and so I kind of just knew straight away they would look after him' [COTB27]; 'We knew if there was anything that we wanted to have done…we sort of left it with [the funeral director]. We had that trust, faith in [the funeral director] that everything with regards to X and preparation would be done' [COTB4]; 'I think we just trusted him' [COTB22].

However, as has been indicated, quantitative work with funeral director respondents indicates that policy and practices as they related to care of the body varied substantially. There was no 'minimum' standard. The funeral directors differed markedly in the actions they took on receiving the body at their premises. Some were of the view that no actions could be taken without family consent, and there was evidence of confusion in the legalities of the case. Others undertook actions they regarded as 'first offices'. Difficulties with conducting the survey underlined the problematic nature of definition: indeed, 'first offices' could, for some funeral directors, extend to embalming the body.

Some funeral director training manual place a strong emphasis on embalming as being beneficial to families, suggesting that embalming is essential to a positive visiting experience: *If the premises provide the right atmosphere, the body is embalmed and properly*

presented, and any visitors are received with courtesy and consideration, the visit can be a comforting experience to the bereaved.[44] In this particular instance, the manual also included persuasive scripts that funeral directors could use to explain the process although it was also noted that families should be *supported in their decision if they choose not to embalm.*[45]

Transparency and informed consent

The Competition and Markets Authority (CMA) investigation concluded with the issue of the Funerals Market Investigation Order on 16 June 2021. This Order requires funeral directors to prepare a 'Standardised Price List' (SPL) for attended and unattended funerals, providing a proforma price list that funeral directors must display in branch and online. The intention of the Order is to arrive at a level of transparency that will allow customers to compare prices. The SPL itemises what is included within standard 'CMA Attended' and 'CMA Unattended' funeral, this latter term equating to what has been termed a 'direct cremation'. Both lists include within '*care of the deceased person before the funeral in appropriate facilities'*, and embalming is listed as an additional itemised service, not automatically included. 'CMA Attended Funerals' include '*viewing of the deceased person for family and friends, by appointment with the funeral director'*. The opportunity to view is omitted from the 'CMA Unattended Funeral'.

'Direct cremation' can be a positive choice for people who have little emotional investment in the dead body. Nevertheless, this research has demonstrated that attitudes differ widely, and many families value the opportunity to interact with the person who has died. Direct cremation is increasingly being regarded as a suitable low-cost option for households on limited incomes, who under the CMA pricing regime would then automatically be denied the opportunity to visit with the deceased at the funeral directors' premises. In aiming to arrive at transparency, the Order may well reduce flexibility.

For the CMA, 'transparency' relates largely to clarity on pricing structures and on premises ownership. It has always been the case that funeral directing, as a profession, has been judged in terms of its commercial dealings. However, funeral directing is not just 'cars and coffins'. *Funeral Experts by Experience* found that a key element of funeral satisfaction was having a funeral director who listened and was responsive rather than directive.[46] Respondents were often acutely aware of an absence of those skills. Within this study, respondents discussing care of the body talked about how decisions were made, and one commented: 'Certainly, I didn't get the feeling they were really exploring what we wanted. I think it was more about what they did. It was more about "the way we [ie the FD] did it" not maybe how we might want it to be done' [COTB4].

Industry Codes of Practice tend to place a greater emphasis on a funeral director's business probity than on their modes of interaction with clients. The Funeral Service Customer

[44] Training manual #1, 19/20.
[45] Training manual #1, 114.
[46] J. Rugg, & S. Jones (2018) *Funeral Experts by Experience: What Matters to Them*, York: University of York.

Standards Review's voluntary Code of Practice was approved in February 2021.[47] The Code binds funeral directors to ten 'mandatory principles' (Box 3.1). Six of these might apply to any business – for example, having due respect for diversity and complying with legal and regulatory obligations. The remaining five are indicated in italics in Box 3.1. These principles point towards the need to act *transparently* and to provide *full and fair information about services*, but the one principle that relates to the body directly simply indicates a commitment to dignity.

Box 3.1: Financial Services Consumer Standards Review Code Principles

1. *act in the best interests of each client, prospective client and customer;*
2. *provide the best possible level of care to the bereaved, keeping in mind the specific needs of each client and family;*
3. *respect and maintain the dignity of deceased people in their care at all times;*
4. *act transparently, with honesty and integrity;*
5. *provide clients with full and fair information about services, products and associated prices;*
6. behave in a way that promotes and maintains public trust in their business, the funeral directing profession and related trades;
7. comply with all legal and regulatory obligations and deal with their regulators in an open, timely and cooperative manner;
8. run their business effectively and in accordance with proper governance and sound risk management principles;
9. run their business in a way that encourages equality of opportunity and respect for diversity;
10. run their business in a way that encourages a culture that values and welcomes complaints as a way of putting things right and improving service; and
11. conduct appropriate due diligence in relation to all third-party contractual relationships that have the potential to negatively impact their clients.

http://www.fscsr.co.uk/fscsr-code-of-practice-guidance/#code

This report proposes that, in preference to 'transparency', the concept of consent creates a more useful framework for guiding activities around care of the body. The medical profession recognises four forms of consent, and three of these are particularly helpful in application to a funerary context.[48] The first and least robust form is 'imputed' consent, by which consent is assumed – in this case – simply through engaging a funeral director. For many funeral directors, care of the body takes place through imputed consent: their services have been secured which in their view signals acquiescence to any mode of body care they regard as being appropriate. The medical profession is generally of the view that this mode of consent provides only a weak foundation for justifying any intervention,

[47] http://www.fscsr.co.uk/fscsr-code-of-practice-guidance/#code. The Code includes eleven mandatory principles and 'Outcomes' under ten separate practice headings. The Code also lists 'Indicative Behaviours' or actions that would be regarded as supporting those outcomes.

[48] See eg A. Smith and J. Parkhouse (2018) 'Informed consent: legal and ethical considerations', *Nursing and Residential Care*, 20:4, 158-161. A fourth form of consent is 'implied', which in a medical setting includes a patient acting in such a way as to indicate consent, for example, winding up a sleeve for an injection.

particularly one where irrevocable change takes place for example as a consequence of surgery.

A second kind of consent is 'presumed' consent. Permission is presumed unless someone gives express dissent and 'opts out'. Presumed consent is generally regarded as ethically justifiable where no harm will follow to the person whose consent is presumed and no change is likely. 'Opting out' is also deemed appropriate where the intended course of action is regarded as personally or socially beneficial, for example, in the case of organ donation. However, 'opting out' is regarded as increasingly problematic where the consequences are potentially harmful and irrevocable. This kind of consent underlies the rubric of the draft Scottish Code of Practice as it relates to first offices and – as indicated above – remains problematic where there is insufficient guidance around the exact nature of first offices. The FSCR seeks alignment with the draft Scottish Code: 'Outcomes' include a presumption that first offices are carried out '*unless otherwise instructed by your client'* and that funeral directors must '*seek to understand your client preferences in relation to first offices at the earliest opportunity'*.[49] However, the Code lists no 'indicative behaviours' in support of those directions.

A third level of consent is 'express' consent, where explicit agreement is secured from a client either verbally or in writing. Where there is a higher level of harm, there tends to be a greater emphasis on the need to secure written consent. It is notable that funeral director manuals often guide practitioners to seek written consent for embalming, and here there is an implicit understanding that this irrevocable procedure requires more active sanction than less intrusive procedures. The FSCSR Code does require a commitment not to perform '*any invasive procedures on a deceased person without first obtaining your client's informed consent'*[50], which introduces questions about modes of securing that consent in a sensitive fashion.

It is appropriate to consider 'consent' on a continuum, with imputed consent at one extreme, presumed consent somewhere in the middle and express consent at the other extreme. The high level of sensitivity around care of the body means that it would be unreasonable to expect fully informed consent to be secured for every procedure enacted on the body under the funeral director's care. Indeed, pushing too far in that direction may well cause high levels of distress to people who are intolerant of that level of detail. However, this report suggests that funeral directors should question their own presumptions around the consent they have secured, and ask themselves whether they have become satisfied with imputed consent and if is ethically correct make no attempt to secure sanction certainly for more invasive procedures.

The final section of this conclusion outlines some reflexive practice notes and offers some guidance on how treatment of the body might be discussed with families.

[49] http://www.fscsr.co.uk/fscsr-code-of-practice-guidance/#codehttps.
[50] At O(3.11)

Documents supporting reflective practice

The report concludes with two documents which support reflective practice in decision-making after death. Box 2 contains some questions that funeral directors might use to reflect on how they generally interact with their clients to secure consent for care procedures.

Box 2: Supporting decision-making in care after death

Supporting decision-making in care after death
Continual improvement through reflection on practice

Consider a specific client/family that you have supported over the last month. Did you talk to them about how the person who had died would be cared for?

If yes,

Information provision

- When and how did you introduce the conversation? Do you feel on reflection that this was the right time?
- How much Information did they want (and how do you know)?
- How much information did you provide?
- Did you specifically ask if they had any questions?
- Was there any language that you used that seemed helpful/unhelpful?

Decision-making and consent obtained

- Which decisions did they make (i.e. what did they give explicit or informed consent for)?

<u>Personal care after death</u>

For the aspects of personal care which someone would also complete during life (i.e. washing, dressing, shaving, make-up application) what kind of consent/agreement did you have from the client?

- Implied consent (the client did not want any information and indicated you could use your judgment in how to care for them)
- Explicit consent (following some information sharing, the client agreed to the aspects of care you suggested)
- Explicit informed consent (you provided information about the care options, the client asked questions and then they made a decision)

In retrospect – was this the right level of consent for the care you delivered?

Funeral-specific care after death

For the aspects of care which are specific to care after death (setting the features, packing orifices, blister management etc) what level of consent/agreement did you have from the client?

- Implied consent (the client did not want any information and indicated that you could use your judgment in how to care for them)
- Explicit consent (following some information sharing, the client agreed to the aspects of care you suggested)
- Explicit informed consent (you provided information about the care options, the client asked questions and then they made a decision)

In retrospect – was this the right level of consent for the care you delivered?

If no,

Information provision

Why did you feel that you could not discuss how the person in your care would be looked after?

Decision-making and content obtained

Personal care after death

For the aspects of personal care which someone would also complete during life (i.e. washing, dressing, shaving, make-up application)

- What care did you carry out?
- How did you decide that this was appropriate?

Funeral-specific care after death

For the aspects of care which are specific to care after death (setting the features, packing orifices, blister management etc)

- What care did you carry out?
- How did you decide that this was appropriate?

For every scenario,

Reflections

Do you feel that there is anything more that you could have done to facilitate the client being able to make more decisions or given more informed consent?

Is there anything that you would do differently next time?

Is there anything that you did that you would apply to your future practice (and maybe share with your colleagues so they learn from what worked well for you)?

This next document offers good practice guidance in decision-making including setting out some key principles underlying that practice.

Box 3: Guidance on good practice to support decision-making

Supporting decision-making and involvement in care after death

Facilitating decision-making

All clients have the right to be involved in decisions about how someone who has died is looked after by funeral directors, and to make informed decisions if they can. Individuals vary greatly in the extent to which they wish to be involved in decisions about how someone is cared for after death, though many are likely to want to make or influence decisions about the care that is delivered.

Clients should have the opportunity to be involved in decision-making relating to all aspects of how someone is physically cared for after death. These decisions should include activities such as first offices, personal care, emergency procedures and embalming.

Some individuals may wish to be given very basic information and the opportunity to ask questions and articulate their preferences broadly. Others may prefer to be given a lot of details and the opportunity to ask more probing questions.

Some individuals will want to be involved in care such as washing and dressing the body. They should be informed of this option from the outset.

The exchange of information between funeral director and client is essential to good decision-making. Serious harm can result if clients are not listened to, or if they are not given the right amount of information and may well need time and support to understand what they are being told. Funeral directors should be confident that at all stages, clients are making informed decisions.

Framework

This is guidance on good practice. It sets out a framework for decision-making that will help funeral directors to practice ethically with regards to care of the body. The following are principles of decision-making and consent.

Principle one - All clients have the right to be involved in decisions about how people are cared for after death and be supported to make informed decisions if they are able.

Principle two – Funeral directors must start from the presumption that all clients may want to make decisions about treatment and care. In dialogue with the client, they might indicate that this may not be the case, but this must not be presumed from the outset.

Principle three – Funeral directors must try to find out what matters to their client so they can share relevant information about the benefits and harms of proposed options and reasonable alternatives, including the option to take no action.

Principle four - Every client has the right to be listened to, the right to information they need to decide, and time and support to understand what they are being told.

Principle five – All clients have the right to be involved in delivering personal care, if that is something that they would like to do

<u>How to support decision-making</u>

Decision-making is an on-going process focused on meaningful dialogue which is the exchange of relevant information specific to the individual and circumstances.

The purpose of the dialogue is:

1) To help the client understand that they can be involved in decision-making and that they have the right to choose how someone is physically cared for

2) To establish how much information the client would like and how much they would like to be involved in the decisions and care. If the opportunity is gently offered then the client will make clear whether they would prefer not to discuss this any further, or whether they would like to understand more

3) To make sure the client has the opportunity to consider relevant information that might influence their choice between the available options

4) To ensure that the client understands the opportunities to be involved in personal care and what the funeral director would do to facilitate this and support them (if this is what they would like to do)

5) To try to reach a shared understanding of the expectations and limitations of the available options and for the funeral director to have established what the client wants

<u>How much information should be provided?</u>

In deciding how much information the client wants, the funeral director should first try to establish a rapport and introduce the subject very gently. The funeral director must explain that the client can have as much information as they would like, and they can be involved in decisions if they want to.

It is preferable to provide small amounts of information incrementally, providing further detail when the client has indicated that this is what they would like. Once the client has indicated that they have been given enough information or indicated that further detail might cause them distress, then the conversation must stop, but on the understanding that the client knows they can discuss this again at a later stage if they so desire.

The exchange of information between client and funeral director is central to good decision-making. It is during this process that the funeral director can find out what is important to a client, so it is possible to identify the information they will need to make the decision.

The funeral director should encourage clients to ask questions. The funeral director should also ask questions to encourage clients to express what matters to them, so it is possible to identify what information about the options might influence their choice.

Funeral directors must make sure the information shared with clients is objective. Funeral directors should be aware of how their own preferences might influence the advice given and the language used. When recommending an option for care, the reasons for doing so must be explained and information should also be shared about reasonable alternatives, including the option to take no action. No pressure should be placed on a client to accept a recommendation.

There are some situations where it would be inappropriate to wait to have the opportunity to gather the views of the client (for example when someone is soiled, and their skin integrity is immediately compromised). In those situations, the funeral director should make decisions in the best interests of their client and person who died. However, actions in these circumstances should be the minimum required so as not to preclude the client making later decisions.

Appendix 4 gives conversation guidance which reflects the principles outlined in this document.

Conclusion

Care of the body in the period between the death and the funeral service can be a largely overlooked element of the functions of a funeral director. High levels of sensitivity often preclude decision-making between the funeral director and families. However, this sensitivity should not preclude a funeral director aiming to achieve a degree of informed consent for procedures, and to actively guide and support families through a decision-making process. Families will show variable levels of tolerance with regard to engagement in this process, and funeral director's personal skills and judgment will play a substantial role in gauging how much information a family requires. 'Transparency' in this case is a

much less useful guiding principle than the notion of consent and the objective of securing a degree of express consent.

Appendix 1: Research instruments

Information sheet

PARTICIPANT INFORMATION SHEET

Care of the body: what do Experts by Experience expect?

Overview

You are being invited to take part in a research study which considers bereaved people's ideas, concerns and expectations how a body is cared for after someone has died (we have described this as personal care). The study also considers how people decide whether to spend time with someone after they have died, and how they reflect on this afterwards. The study seeks to understand people's experienced prior to the Coronavirus pandemic in 2020 and therefore participants will be asked to discuss experiences of funerals from 2019, or before.

Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part.

Further information

What is personal care?

Person care of the body refers to all the actions that are performed on or to the body of someone who has died. This might include where they are located and activities such as washing, dressing and embalming (sometimes called hygiene treatment).

The research team will ask a small number of people some detailed questions about their thoughts and reflections about how someone is cared for after they had died. We will ask these questions in the context of a funeral that you have arranged or been closely involved with.

What is an "Expert by Experience"?

An "Expert by Experience" is someone who has personal experience of using health and/or social care services. In health and social care research, the perspective of people with this lived experience is increasingly being prioritised and used to understand how to deliver and improve services. This is regarded as a positive move away from only asking professionals (such as funeral directors) for their opinions.

What are decisions about spending time with someone?

The research will ask whether you decided to spend any time with the person who had died, after they had died. You will be asked open questions about how you decided whether this was something that you wanted to you and then asked to describe this experience and how you felt about it then and now.

What is the purpose of the study?

A recent research study (report can be found at https://fullcirclefunerals.co.uk/learning-together/research/) highlighted that it is important to bereaved people have different views regarding spending time with someone who has died but that the important factor is that their individual needs are understood and met. During this study, we did not specifically ask people for their ideas, concerns or expectations about how the body had been cared and this current study seeks to understand that further.

Different funeral directors have varying ways of practicing and caring for people who have died. The funeral industry has been criticised for not being open and transparent with the people who use their services and this research group feel that this also applies to care of the body. The findings of this study will be used to make recommendations for good practice to funeral directors and allied health and social care professionals.

Why have I been chosen?

You have been chosen to participate in this study because you have attended the funeral of a close relative and feeling willing and able to discuss your experience without this causing you any undue distress or anxiety.

Do I have to take part?

No. It is up to you to decide whether to take part. If you do, you will be given this information sheet to keep and asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or decision not to take part, will not affect and support that you may require from us in the future.

What will happen to me if I take part? / What do I have to do?

If you agree to take part in this research, we will ask you to answer some questions with one of our researchers. This can take place over the telephone, or via video interview depending on your preference. This interview is likely to take between half an hour and one hour and be recorded on an

encrypted recording device. This means that we can concentrate on the conversation and be able to write the detail down accurately afterwards.

What are the possible benefits of taking part?

This study will improve our understanding about what is important to bereaved people regarding personal care and spending time with someone after they have died. This research ultimately aims to increase our understanding of how funeral directors (and allied professionals) can support bereaved people in the best possible way.

What are the possible disadvantages and risks of taking part?

There are no specific risks to participating in this study. However, as with all bereavement and funeral related research, you may feel upset when answering the questions as they ask you to discuss a funeral, and your feelings about certain aspects of it, in some detail.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice at all times and all information about you will be anonymised and handled in confidence. However, if you were to divulge information that could potentially lead to prosecution or may expose children, vulnerable adults or the general public to serious risk then this information may need to be reported. In these unlikely circumstances, all efforts would be made to discuss this with you before any information is disclosed.

Expenses and Payments

No payments will be provided to participants in the study. It is not expected that any expenses will be incurred.

What will happen if I don't want to carry on with the study?

You can withdraw from the study at any time and this will not affect any future support that you may request from us.

What if there is a problem?

If you have a concern about any aspect of this study, we will want to know. Please speak to the researchers who will do their best to answer your questions (see contact numbers given). If you remain unhappy and wish to complain formally, you can do that by contacting Fran Hall from The Good Funeral Guide.

Full Circle Funerals – 01943 262626

Fran Hall (CEO Good Funeral Guide) – 07866 596234

Will my taking part in this study be kept confidential?

Your participation is voluntary, and all information will be kept confidential and anonymous. All information will be kept strictly confidential and will be held a password protected electronic file. Instead of using your name you will have a unique research number.

The initial interview will be recorded using an encrypted recording device and this will then be transcribed. This document will have unique research number but will not contain any personal identifiers (such as names or places). Once the interview summary has been created, the recording of the interview will be permanently destroyed.

Data linking your unique research number to your personal details will be stored securely, in a password protected electronic file. This information will only be kept beyond completion of the study if you have specifically consented for this to take place, as you would like to informed of opportunities to be included in research studies carried out by Full Circle Funerals in the future.

What will happen to the results of the research study?

The results from this study will be published as a written document, and possibly published in a scientific journal. The results will also be presented at conferences. In all instances, your details will remain anonymous and all information remains confidential.

Who is organising and funding the research?

The project is being carried out by the Full Circle Funerals (an independent Funeral Director based Yorkshire). There is no funding in place for this study.

Who has reviewed the study?

Full Circle Funerals is receiving support from an advisory committee, including representatives from the University of York, ICCM (Institute of Cemetery and Crematorium Management), GFG (Good Funeral Guide), SAIF (National Society of Allied and Independent Funeral Directors).

Thank you for taking the time to read this information sheet, please keep it for your future reference.

Contact for further research information:

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Full Circle Funerals
114 Otley Road
Guiseley, LS20 8LZ
Tel: 01943 262626
Email: sarah@fullcirclefunerals.co.uk

Topic guide

CARE OF THE BODY TOPIC GUIDE

Setting the scene

- Please could you start by telling me whose funeral you are happy to talk about?
    - Establish relationship to person who has died
    - When was the death? [useful to know if it was very recent]
    - If appropriate, explore the quality of relationship and any contributing interpersonal dynamics
    - Establish how long ago the funeral occurred

- Can you start by telling me about events leading up to the funeral?
    - Might include illnesses / sudden death
    - May give indication of nature of death / coroner involvement

Communication with the funeral director

During this part of the interview, "the body" should be replaced with the person who has died's name / title (i.e. Mary or your mum) if that is what the participant is using

We want to talk in some detail about your experience of the way the funeral director talked to you about how they might care for the body of [NAME HERE]. We understand that we may be calling on you to remember distressing things, so we'll take it slowly and you can stop at any time.

Are you happy to proceed?

If yes, I would first like to ask you about what happened, right at the beginning, when you first contacted the funeral director
What did the funeral director tell you would happen with the body?

Did the funeral director ask you how you would like the body to be cared for?

Did you have any clear wishes, if so, – could you explain why you wanted that?

Did you feel at the time that you were given enough information?

- about the (very invasive) procedures: eg embalming, setting the features
- about the decisions you could take eg about body care, dressing, visiting?

What happened with the body

We want to talk in some detail about your experience of the way the funeral director cared for the body of [NAME HERE]. As before, we'll take it slowly and you can stop at any time.

Are you happy to carry on?

If yes - where was [name] immediately before coming to the funeral director?

If it was at their home - how was the body was transported to the FD? Did you see that?

How did you feel about that experience?

How did the funeral director tell you *from that point*, what was happening with [name]:

- in terms of basic personal care
- where [name] was being looked after (storage type and locations)
- Whether they needed to be taken anywhere (for example to the GP for cremation paperwork to be completed)
- in terms of any invasive procedures [eg embalming]
- preparing the body for visiting (eg did they ask for a photograph?; did they ask for clothing?)

When/how did the funeral director tell you that it was possible to come and visit?

Did the funeral director ask you about your preferences for the visit (eg in/not in a coffin)

Visiting with the body

Did you decide to spend time with [Name's] body while they were at the funeral director? Please can you explain how you came to that decision?

If no – proceed to summary (a) only
If yes – proceed to questions below

Can you tell me first about how you arrived at the funeral directors': did you have to make an appointment?
Did the funeral director say anything before you went in to visit with [name] for the first time?

What did you expect to see?

We want to talk in more detail about the visit, so we are going to break it down and talk about it a bit at a time, if that's ok

Did you visit with anyone?

- Please can you tell me how that decision was made?

Tell me about the room, what was it like?

- atmosphere, chairs, 'feeling' ie comforting, clinical

Was [name] lying on some kind of bed or in a coffin?

How was the body posed (eg arms crossed, hands clasped)?
- Did the pose matter to you at all?

Did the face have any particular kind of expression?
- Was the expression important to you?
- Funeral directors may use certain techniques to close someone's mouth and close their eyes – are you aware of whether this was the case?
- Do you know what these techniques are?
- How do you feel about that?

What about the hair and any other features (eg glasses)?

Had the funeral director used make-up at all?
- How did the person look to you?

Did you touch [name] at all? What was that like?

Did you feel that you could stay as long as you wanted to?

Did you visit again? Was it different a second time?

How often did you visit, in total?

Afterwards

What happened when you came out of the room after the first visit?

Overall, do you feel you had enough support for that first visit?

Do you think you were adequately prepared for it, by the funeral director?

Now proceed to summary (a) and (b)

In summary

These questions should only be asked if this has not already become clear during the interview – unnecessary repetition should be avoided… be selective

(a) Did you feel afterwards that you had been given enough information about how [name's] body was cared for?

Do you think you were given enough choices about what would happen?

Did you feel that you were in control of the situation?

Overall, did you feel that the funeral director gave you enough support in terms of all the decisions relating to the treatment of [name's] body?

How do you feel about the physical care of [name's] body?

What would you have done differently (if anything), in terms of this funeral?

(b) How do you feel about your decision to visit / not visit and the experience of any visits?

Recommendations

We want to put together a short list of the things funeral directors should remember, in thinking about the treatment of the bodies in their care. What for you would be the three most important things to put in the list?

If necessary, ask them to elaborate on the three recommendations they have made to seek further clarity.

Demographic

Please could you answer a few simple demographic questions?

What would you say your gender is?
What is your ethnicity?
What is your religious persuasion?
What is the first part of your postcode?
And how old are you?

Appendix 2: Quantitative funeral director survey respondents

Scale of operation		
One branch	134	49.4
2-5 branches	101	37.3
More than five branches	36	13.3
	271	100.0

Catchment area		
Local	256	94.8
Regional	14	5.2
	270	100.0

Main area of operation (respondents could indicate more than one)	
South East excluding London	55
London	20
South West	38
West Midlands	18
East Midlands	18
East of England	16
North East	13
Yorkshire & Humberside	25
North West	27
Scotland	24
Wales	15
Northern Ireland	4

I would describe our business as…		
Traditional	109	40.5
Modern	33	12.3
Alternative	1	0.4
Progressive	22	8.2
I would not wish to label our business	16	5.9
All of the above	88	32.7
	269	100.0

Appendix 3: Demographic information on qualitative respondents

Gender		*Religion*	
Female	27	Christian (CoE, 'Christian', RC)	11
Male	3	Buddhist	2
		Jewish	2
Age		'Spiritual'	2
20s	2	Jain	1
30s	1	None (including Atheist, Agnostic)	12
40s	7		
50s	9	*Location*	
60s	9	Yorkshire and Humberside	12
70s	2	London/South West/South East	8
		East/East Midlands	3
Ethnicity		Scotland	1
Black African	1	Location not given	6
British Asian	1		
Mixed	1		
White British	27	Total number: 30	

Appendix 4: Conversation guide for funeral directors

Conversation guide
Supporting decision-making about care after death

This framework will help you to support clients to make decisions about how someone is physically cared for after death, and whether they would like to participate in delivering this care.

Conversation flow
Set up
⬇
Assess understanding and information preferences
⬇
Share preliminary information
⬇
Explore key areas
⬇
Close conversation

	Conversation flow	Suggested language
Set up	1) Introduce topic of conversation	We would like to talk to you about how "name" is looked after while they are in our care.
	2) Acknowledge that this can be a difficult conversation for many people	This can sometimes be a difficult thing to talk about but many people find it helpful to be involved in decisions about care
	3) Reassure that you will support them to be involved in decisions and care, without forcing them to talk about anything they are uncomfortable about	Some people find it meaningful to be involved in personal care, for example washing, dressing, or styling "name's" hair. If that is something that you would like to do then we are able to support you with that.
Assess understanding and preferences	2) Acknowledge that different people in the room may want different amounts of information	Some people might feel more comfortable talking about this than others, what do you think?
	1) Establish whether they would be happy to discuss this now	Are you happy to talk about this now, or would you rather that we come back to this at another time?

IF THEY WANT TO DEFER THE CONVERSATION

Keeping options open	Establish what a minimum intervention means at this stage	We will take "name" into our care, and make sure that they are washed and comfortable. We can come back to this another time.

If the client is not yet ready to discuss care after death, then you should complete the actions that you think are required to prevent harm and fulfil your responsibilities to deliver adequate care. These activities are likely to depend on the individual in your care, circumstances of their death, what statutory paperwork has been completed, your approach and philosophy of care. You must document the actions that you have chosen to undertake and why.

IF THEY WANT TO HAVE THE CONVERSATION

Share preliminary information	1) Provide very basic information about facilities and minimum care 2) Explain that there are options 3) Seek their feedback about how much information they would like	After someone has died, it is important that they are kept cold and safe. We can do that here. Beyond that, there are several ways that we can care for someone and that depends on what you would prefer, and what you think they would have wanted. Some people prefer for us to do very little more than make sure that they are safe. Others would like us to wash and dress the person who has died. There are also other things that we can do look after people and which affect the way that they look. For example, it might be important to you that "name's" eyes and mouth are closed. There are times when it might be worth considering whether someone has died is embalmed. That is something that we can arrange, and I can share some more information about that if you would like me to.

Explore key areas	1) Provide more information if requested but do so in small increments – you can always give more but cannot easily retract information provided 2) Continue providing information incrementally until the client indicates their information needs have been met 3) Language must be chosen carefully and be accessible to people unfamiliar with funeral care practices	Do you have any thoughts about how you would like us to look after "name"? Is there anything that you would like me to tell you more about? We can often ensure that someone's eyes and mouth are closed by carefully positioning their head a certain way. Sometimes this positioning doesn't work and then there are other things that we can do to make sure their eyes and mouth are closed. Would you like me to tell you more about that? Some people would like to know more details, whereas others would prefer to tell us how they would like someone to look and then leave us to decide how we can best achieve that. Embalming is a process whereby bodily fluids are replaced by a chemical which aims to stop nature taking its course. I would be happy to talk you through the procedure in more detail, if you think that would be helpful. If you would like "name" to be embalmed, then there is a consent form that I need you to sign.
Close conversation	1) Summarise outcome of conversation (and document, if appropriate) 2) Reassure that you are open to further conversations / providing more information if the client would like you to at a later stage	I have listened carefully to everything that you have told me – thank you. As with all the decisions that you are making, you might change your mind over the coming days – please just let me know if you would like to talk about this again