

# Legal needs of adults with life-limiting illness: what are they and how are they managed? A qualitative multiagency stakeholder exercise

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## ABSTRACT

**Objective** Little is known about legal needs in the context of life-limiting illness, particularly the need for advice concerning legal arrangements, rights and entitlements. This UK-based multiagency stakeholder engagement exercise scoped legal needs associated with life-limiting illness and identified support structures, gaps and opportunities for practice improvement.

**Method and analysis** Snowball sampling generated a stakeholder group from a wide range of regional and national organisations involved in care of people with life-limiting illness, spanning health, social care, legal support, advice, charities, prison services as well as patient and carer representatives. A coproduced survey of three open questions generated qualitative data, interpreted by thematic analysis.

**Results** Stakeholders reported a broad spectrum of problems and needs raising legal issues, with no consistency of definition. A classification is proposed, identifying matters concerning rights and entitlements of patients/carers in day-to-day life and decisions around care, both immediate and in the future, as well as professional responsibilities in delivering personalised care. The support structures identified were predominantly online literature, although there was some availability of remote and face-to-face services. Limited awareness of the issues, variable service configuration, fragmentation of care and inequitable access were identified as barriers to support. Stakeholders recognised the need for education and closer multiagency working.

**Conclusions** 'Legal needs' incorporate wide-ranging issues, but there is inconsistency in perceptions among stakeholders. Practice is variable, risking unmet need. Opportunities for improvement include more formal integration of social welfare legal services in the health context, generating clearer pathways for assessment and management.

## BACKGROUND

Holistic care is an integral component of the palliative care approach in the UK, acknowledging that serious illness generates a wide range of concerns and challenges experienced by patients and their carers. Assessment of needs across a range of domains is advocated for people living towards the

## What is already known about this subject?

- ▶ Life-limiting illness generates significant challenges for patients and carers, relating to care and day-to-day life.
- ▶ Holistic assessment is advocated for patients in a palliative phase of illness but has not been widely adopted into routine practice.
- ▶ Patients and carers access advice and support from a wide variety of sources, including clinical services, social care providers, advice services, charities and legal professionals.

## What does this study add?

- ▶ Legal needs consequent to life-limiting illness are broad. We propose a classification into issues around healthcare and issues around daily life. Both relate to immediate needs and planning ahead.
- ▶ Some support to manage legal needs is already available but may not be easily or equitably accessible.
- ▶ Delivery of holistic care requires identification of broad social welfare legal issues as well as better integration of the wide range of organisations that offer advice and support.

## How might this impact on clinical practice or future developments?

- ▶ The classification of legal needs in the context of life-limiting illness offers a foundation for raising awareness and delivering more consistent holistic approaches to care.
- ▶ There is a need for workforce education to raise awareness and improve practice in this area.
- ▶ A national approach to integrated care across the multiagency team is needed; health justice partnerships warrant further evaluation in the context of life-limiting illness.

end of life,<sup>1</sup> and this is expected to translate into personalised, holistic care of patients and carers, integrating the wide health and social care system.<sup>1,2</sup> Assessment tools have been developed to support this process, such as the Symptoms and Concerns Checklist<sup>3</sup>

and Sheffield Profile for Assessment and Referral for Care.<sup>4</sup> Responsibility for supporting holistic assessment is broadly defined as ‘the individual’s health and social care team at each key point’.<sup>5</sup> However, despite national promotion, holistic needs assessment has not been widely adopted into routine clinical care.<sup>6</sup>

Law and health interact in a number of ways. Prominent legal cases and ethical debates, such as around assisted suicide, are newsworthy and widely recognised. Legal frameworks, such as the Mental Capacity Act 2005,<sup>7</sup> define rights and responsibilities within care delivery. Much less obvious, however, are the social welfare issues consequent to chronic illness. These relate to matters of daily life, including income security, suitable housing, employment rights, family issues, immigration, protection from abuse and the right to community care.<sup>8,9</sup> The law defines rights, entitlements and protections around these issues, generating an important interface between health and law.

Despite the intention of holistic care, these social welfare legal (SWL) needs are frequently overlooked, impacting negatively on physical and mental health (and vice versa)<sup>10</sup> as well as increasing health service utilisation.<sup>11,12</sup> Professionals may lack awareness of needs, relevance to health and routes to support; people seeking help often view these problems as non-clinical and fail to identify a route for support.<sup>8</sup> Other challenges that obstruct holistic needs assessment, such as time, professional confidence and lack of available services to refer onto,<sup>6,13</sup> compound the problem.

While there is a broad range of services supporting legal needs in the context of life-limiting illness, spanning health, social care, advice, charitable and legal sectors, it is not clear whether there is consistency in language or approach to these needs. These services are not routinely integrated within the multidisciplinary team delivering palliative care, nor are there clear pathways to access support.<sup>8</sup> There is no national guidance on when and how services providing advice and support for legal needs associated with ill-health should be engaged, risking variable practice and unmet need.

This qualitative multiagency stakeholder engagement exercise was designed to scope perceptions of legal needs, support structures and gaps. It forms part of the Legal Needs of Adults with Life-Limiting Illness (LeNA) research programme, developed to build understanding of legal issues in the context of life-limiting illness. The findings are expected to inform current work developing a national approach to integration of SWL provision into health services.<sup>14</sup>

## METHODS

Methods used in this coproduced scoping study were: (1) the establishment and maintenance of a national multiagency stakeholder group whose membership was a mechanism by which to map current provision and gaps in service and (2) a short coproduced survey administered

via either email or telephone according to preference to scope perceptions of legal needs, support structures available and perceived gaps in service provision.

A stakeholder group was identified, through established links both regionally and nationally via a process of snowball sampling in which responders to an initial scoping email suggested other stakeholders. Stakeholders were defined as any private or public organisation with a remit relating to health, social and/or SWL needs in adults with life-limiting illness and/or their carers. Wide representation was sought to ensure engagement with an appropriate breadth of services. Stakeholders included charities, advice services, health and social care providers, service user representatives, prison services and legal professionals. Organisations were contacted and offered a telephone introduction to the project. Between September 2017 and June 2018, participating organisations were invited to respond to three open-ended survey questions by email or telephone call. These qualitative questions were derived by a synthesis of literature review alongside coproduction and piloting with a core, multi-disciplinary stakeholder group. Members, including informal carers and professionals from health, social care and legal services, were asked to identify their top priorities by email, followed up with a round table discussion in which the following questions were agreed:

1. What you would include in a list of ‘legal issues’ experienced by people living with life-limiting illness?
2. Does your organisation provide any information or services relating to legal issues (in any form—written, online, telephone or face to face) available to people living with life-limiting illness? Please specify everything relevant and include links to view online material.
3. Are you aware of gaps in support/information/services relating to legal issues in this client cohort? Please specify these.

Core stakeholder group members (excluding informal carers) also contributed responses to these questions that were included within the data. Project governance was provided through the hospice education and research group.

Data from email responses and telephone interviews were transcribed into a spreadsheet that was then used to code the data. Thematic analysis<sup>15</sup> of responses was undertaken by CH who also reviewed all online material offered by stakeholders; HC reviewed the analysis and both agreed on data saturation. Sampling stopped when data saturation was reached (ie, when no new themes emerged from the data). All participating stakeholders were asked to review collated findings, and any additional comments were incorporated. The engagement exercise was not intended to be exhaustive but rather to provide a breadth of views on how stakeholders define and support legal needs in this context.

## Patient and public engagement

The core stakeholder group included bereaved carers who were able to input to the programme of research.

This group met twice in the first 6 months to support project design and also shared ideas and feedback electronically throughout the project duration. An example of impact was the carers' input to survey question design, through the insights they offered from lived experience. At the end of the study, they commented on the findings and contributed to the dissemination plan.

Standards for Reporting Qualitative Research (SRQR) reporting guidelines were used in manuscript preparation.<sup>16</sup>

## RESULTS

The majority of stakeholders approached expressed a strong desire to offer time and input to the project because of a collective, and often passionately held, view that legal needs are underacknowledged and are often unmet, or at best are addressed by variable services in a reactive, uncoordinated manner. In addition to providing factual answers to the questions above, participants also volunteered views about how and why these services, gaps and issues are experienced, and in some cases, email clarification on meaning was sought. A total of 38 stakeholder representatives were included from 36 different organisations, including:

National charities (appropriate representative identified by each): Age UK, Alzheimer's Society, British Lung Foundation, Compassion in Dying, Disability Law Service, Family Action, Hospice UK, LawWorks, Macmillan Cancer Support, Marie Curie, MND Association, Parkinson's UK and Sue Ryder. The Relatives and Residents Association and Maggie's Centres were approached but did not proceed, and websites of Carer's UK and Independent Age were reviewed for information about resources and services in the absence of a project liaison.

National support organisations (appropriate representative identified by each): Advice Services Alliance, Citizen's Advice Bureau, Digital Legacy Association, Money Advice Service, National Bereavement Alliance and Together in Dementia Everyday. The Association of Palliative Care Social Workers engaged with the project following completion of this phase.

Local or North East region service providers professionals were recruited (numbers in parentheses) from services representing a wide range of diagnoses and elements of care provision including:

Clinicians: specialist palliative care (4), General Practitioner (GP) (1), dementia (1), motor neuron disease (1), multiple sclerosis (1), Parkinson's disease (2), chronic respiratory disease (1), heart failure (1) and hospice-based social workers (3).

Support services: Macmillan Cancer Information Centre manager (1), welfare benefits advisor (1), hospice community liaison officer (1), adult social services manager (1) and Fulfilling Lives (complex social needs charity) lead (1).

Others: carer representatives (3), immigration solicitor (1) and end-of-life lead for Durham Prisons (1).

A university academic provided a perspective on assisted suicide. Experience of the authors (CH in palliative care and MK as founder of Legacare) provided additional insights.

## Responses to baseline questions

Responses across the three questions were diverse, revealing significant breadth of issues perceived to have a legal context. There was wide variability in how service providers perceive legal needs and practitioners' working definitions reflected, and were mostly limited to, their particular disciplinary focus. Thematic analysis of questions 1 and 3 classified legal needs towards end of life into two key areas: health and day-to-day life. Both were further divided into current concerns and planning for the future and into rights and responsibilities of individuals receiving care and professional responsibilities in care delivery (table 1). Cross-cutting themes included: understanding and application of the law, understanding rules and processes and ethical decision making.

### Scoping 'legal issues'

#### Health: current concerns

Responses identified individual rights to safe, legally compliant care and the professional responsibilities around these. Lack of knowledge, professional disagreements and difficulty in enacting legal frameworks or professional guidance/standards were frequently flagged by stakeholders. These included The Mental Capacity Act,<sup>7</sup> Mental Health Act,<sup>17</sup> Human Rights Act,<sup>18</sup> Deprivation of Liberty Standards,<sup>19</sup> surveillance and restraint, Court of Protection, safeguarding, advocacy, consent, withdrawal/with-holding of treatment and assisted suicide.

Lack of understanding by patients and families about consent on behalf of their spouse or other family member. They assume that being next of kin entitles them to make decisions. (Carer group representative)

Various groups were identified as raising particular concerns around equitable access to care or challenges when interpreting and applying the law. This was a diverse group, broadly identified as 'disadvantaged'. It encompassed people with more complex needs including homeless, challenging behaviours, learning disabilities, dementia, mental health issues, communication difficulties; people in deprived or isolated communities; and people in marginalised or discriminated groups, including asylum seekers, Lesbian, Gay, Bisexual, Transgender (LGBT) people, travellers and prisoners. Issues included the right to National Health Service (NHS) care, access to healthcare including specialist services and the attitudes and behaviours of professionals that impact negatively on service users, including elder abuse.

Legal issues relating to death included verification of death and the importance of cultural and/or religious sensitivity, death certification, postmortems, involving the coroner and compensation relating to diagnosis.

**Table 1** Classifying 'legal issues'

	Individual Rights/Responsibilities	Professional Responsibilities
Healthcare: current	Empowered to make decisions Access to services Rights of disadvantaged groups	Professional frameworks for care delivery, including after death. Interprofessional team working (across health, social, legal and advice services).
Healthcare: future	Empowered to plan Rights of disadvantaged groups	Enabling advance care planning (including opening conversations). Rules around donation. Interprofessional team working (across health, social, legal and advice services).
Day to day life: current	Social care Finances and benefits Employment Informal carers Travel Voting Responsibilities after death	Awareness, assessment/identification, support and/or signposting. Interprofessional team working, including when to involve legal services.
Day-to-day life: future	Financial planning Home ownership Guardianship Social media Non-traditional contexts/relationships	

### Health: planning for the future

Responses focused on the principle and application of advance care planning (ACP). This went beyond the legally binding elements to wider issues such as lack of clarity around responsibility for initiating and supporting conversations, how and when to engage legal professionals and the challenge of sharing ACP information. Body, organ and tissue donation was raised in terms of understanding the rules, open discussion and supporting choice.

Again, certain groups were raised as potentially disadvantaged by barriers to planning ahead.

Healthcare professionals can find it difficult to know when a person with multiple and complex needs requires end of life care, our clients have conditions with uncertain prognosis, such as drug or alcohol-related liver disease, have less interaction with healthcare professionals, especially in primary care and on average die younger than most people referred for end of life care. (Fulfilling Lives Newcastle Gateshead)

### Day to day life: current concerns

Legal issues within this theme included:

- ▶ Finances: social security benefits, paying for social care, continuing healthcare processes and decisions, accessing pensions or insurance funds and managing debt.
- ▶ Employment: rights and responsibilities of both employers and employees, leaving work and discrimination law.
- ▶ Social care: access to and funding of care delivered in the person's own home or in a care setting and

individual rights including routine, cultural sensitivity and managing challenging behaviour.

We hear from carers that care home staff may ask them not to visit for the first two weeks (so that the person can settle!). When receiving care at home we hear lots of issues around not being cared for appropriately/not being bathed/being put to bed in the early evening/not having sufficient time to have their meals prepared and supported to eat. Most of these challenges would be breaches under the Human Rights Act. (Together in Dementia Everyday)

- ▶ Carer issues: accessing respite, support and information to enable caring role, accessing support in own right and education needs for young carers.
- ▶ Travel: fitness to drive including Driver and Vehicle Licensing Authority rules and vehicle insurance, disability support, support for travel costs, travel abroad including insurance and travelling with drugs and repatriation.
- ▶ At death: registering a death, bereavement rights and benefits, informing agencies and managing the estate.
- ▶ Voting rights.

### Day-to-day life: planning for the future

Stakeholders identified financial planning (writing a will, protecting assets and prepaid funeral plans), home ownership (including rights of unmarried partners or family members), guardianship of dependents, writing a social media will and the legal status of people in non-traditional contexts such as asylum seekers and travellers.

### Currently available resources and services

There is significant online literature available relating to the most commonly identified needs. Charities and advice/support organisations usually present their own information generating duplication that proved difficult to navigate. Much of the online information is also available in paper format. Online professional information includes guidance around assisted dying<sup>20</sup> and advice around the needs and rights of disadvantaged groups.<sup>21</sup>

Some organisations offer online communities, webchat advice or telephone advice. While face-to-face services are widely available, most offer specific areas of advice or support, often to specified client groups.

### Gaps

Stakeholders recognised significant gaps in support for legal issues. Analysis revealed three main themes: gaps in service provision, obstructions to delivery of high-quality care and opportunities for improvement.

#### *Gaps in service provision*

Service provision was recognised as inequitable and variable, with particular concern raised for people with non-malignant diagnoses, disadvantaged groups in society and isolated communities. National variability in access to welfare rights and health-related legal services was highlighted. Challenges to social care provision were flagged, with difficulty accessing appropriate domiciliary social care especially for people living alone, with elderly carers, with overnight needs or with challenging behaviour.

Access to the internet was a potential barrier, given the current prominence of online support. Lack of help to complete long or complex documents, such as lasting power of attorney, was seen as a common reason for people abandoning tasks.

#### *Obstructions to delivery of high-quality care*

A number of obstructions to delivery of high-quality care were identified by stakeholders. Concern was raised that patients and carers may not know how and where to raise concerns that are not obviously clinical. Health professionals may not ask about SWL needs through lack of awareness and/or limited adoption of holistic needs assessment tools, which themselves are restricted in breadth. Service fragmentation, inadequate understanding of support structures and routes to access these create additional barriers to care. Lack of confidence to initiate discussions around end-of-life choices and difficulty implementing knowledge of legal frameworks into clinical practice were also reported. Carers were presented as frequently excluded from decisions and disempowered.

Inconsistency in advice and practice was identified, including continuing healthcare assessment pathways, admission criteria for hospices and care homes and approaches to free NHS care for immigrants and asylum seekers. Perceived cost of legal advice was a potential barrier to support.

Finally, more general challenges relating to end-of-life care included difficulty prognosticating and carrying out wishes. A battle mentality, both between professionals from different disciplines and patients/carers feeling they had to fight for their rights, was a more challenging theme.

#### *Opportunities for improvement*

These mirrored the common themes raised, including professional education to increase awareness of the breadth of SWL needs, respective roles and responsibilities in meeting these needs and pathways to support. Closer integration of all relevant agencies, spanning health, social, advice, charitable and legal services was identified as necessary to enable holistic care delivery. Advice and support offered earlier in a disease journey was likely to benefit patients and carers; a toolkit to help professionals navigate legal issues was also proposed.

### DISCUSSION

Stakeholder engagement, capturing perspectives across a diverse range of agencies, revealed a previously undocumented breadth of issues with a legal dimension within the context of life-limiting illness. Responses enabled classification of legal needs into healthcare and matters of daily life, both current and future planning, acknowledging the rights of individuals and the professional responsibilities in care delivery. This is the first known study to reveal that stakeholders have significant variation in perceptions of legal needs, highlighting the importance of clearer understanding to enable greater consistency in approach. The proposed classification in this paper provides a starting point for a future framework of service provision.

Resources and services were identified that help people navigate through these issues including literature, remote and face-to-face support. However, a number of gaps in support were identified by stakeholders, limiting the effectiveness of these support structures. These included: lack of awareness of the issues and currently available support, failure to assess, fragmented and disconnected services with no signposting or clear referral pathways, perceived cost of legal support and bias towards online information. Accessibility was a concern with particular reference to exclusions around diagnosis, personal status and locally determined service referral criteria. This urgently needs attention if the strategic ambitions<sup>2</sup> around equity and the right to personalised end-of-life care are to be realised.

Stakeholders shared a collective desire for change and had a shared vision for opportunities for improvement. These included: holistic assessment incorporating broad SWL issues and integrated multiagency working with clearer links across health and social care into the advice, charitable and legal sectors. The need to raise awareness of the breadth of legal issues experienced in life-limiting illness, both with professionals and patients/carers themselves, was a strong theme from stakeholders.



Empowerment of patients/carers to help themselves, where appropriate, was a valued outcome. The important role of education, for both providers and recipients of care, was highlighted.

### Strengths and weaknesses of the study

The study is the first of its kind to explore how legal needs associated with life-limiting illness are perceived by providers of care. Representation of a wide range of stakeholders across multiple sectors and organisations offers breadth of perspective. However, limits to the number of care providers involved, both in terms of organisations and individuals, means inclusion was not exhaustive, and it is possible that important issues, resources or services have been omitted. Data saturation indicates identification of key issues although the methods do not allow unbiased determination of the relative importance of the issues. Further work is needed to map solutions to the problems raised across the UK.

### Implications for practice

Law and health are fundamentally linked, with ill-health generating legal problems, such as debt and unemployment<sup>9,10</sup> and SWL problems, such as poor living conditions, causing or exacerbating ill health.<sup>9,10,22</sup> If unmanaged, these issues can spiral.<sup>23</sup> Barriers to accessing help include individuals unaware of their rights, not knowing how to access help or assuming that challenges are inevitable.<sup>24,25</sup> This indicates the importance of professional structures for assessment and support.

Health justice partnerships, collaborations between legal and health professionals, provide free support for disadvantaged and vulnerable patients with health-related legal issues in the USA<sup>26</sup> and Australia.<sup>27</sup> Despite variation in the set-up and delivery of integrated services, these have shown a positive impact on finances<sup>28</sup> and health and well-being<sup>29</sup> as well as reducing GP workload.<sup>30</sup> While a number of partnerships between health and SWL advice services already exist in the UK, many are locally defined and operate on short-term funding.<sup>14</sup> Our findings indicate that legal and advice services are not generally considered part of the multidisciplinary end-of-life care team in the UK.

This study challenges policymakers and care providers to consider how to deliver a more consistent holistic approach, for example, by establishing better links between health services and community SWL services and by making use of social prescribing link workers in general practice.<sup>31</sup> While there are resources and services to support legal needs, findings from this study also raise the importance of open dialogue about accessibility and provision of equitable care to meet this broad range of needs. The study highlights the growing sense of commitment at ground level to address legal issues. There is a real opportunity for an integrated, multiagency model of care, extending beyond health and social care to include the breadth of organisations working to improve the experience of patients and their carers. This is currently

under consideration at national policy level,<sup>14</sup> and further work to develop and evaluate models of care and education is underway.

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**Contributors** CH: chief investigator of the Legal Needs of Adults with Life-Limiting Illness (LeNA) project and lead of stakeholder exercise including identification and communication with stakeholders, thematic analysis and draft publication. HC: senior methodologist to the LeNA project and methodology of stakeholder exercise, review of data analysis and critical review of publication. MK: contributed to the LeNA project concept, supported stakeholder identification, stakeholder group member and critical review of publication. HG: expert advisor to the LeNA project, supported stakeholder identification and critical review of publication. All authors have approved the final submitted version. All authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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