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Working with terminal illness: what is known and what is needed

**Experience of terminal illness in working-age people:
a review of the literature and a survey of HR professionals**

THE QUICK READ

Terminal illness affects people of all ages. In partnership with Marie Curie, we explored what is known about working with terminal illness, and what needs to change.

Our **scoping review** identified four areas where we need to build the evidence of 'what works' for employers, individuals and policy makers to support people working with a terminal illness:

1. Social, welfare and legal needs.
2. Financial needs.
3. Mental wellbeing needs.
4. Factors affecting decisions to work.

Our **survey of over 1,000 UK Human Resources (HR) decision makers, conducted by YouGov, revealed:**

- An 'employer lottery' where access to type of support varies significantly.
- Support and reasonable adjustments provided include flexible working, managing sickness absence outside of standard reporting systems, changes to duties, provision of insurances, and direct financial support.
- Offering flexibility, creating an open, inclusive and supportive culture, and having sensitive and supportive conversations would be most likely to improve the experience of people working with a terminal illness.

As the population ages, works longer, and disease treatments continue to improve, it is highly likely that more people will be working with a terminal illness. There is an urgent need to build consensus on measures of workplace wellbeing in this context, and develop the evidence of 'what works' to effectively support employees.

What we did

We designed and commissioned a **scoping review** of peer reviewed and grey literature to understand what is currently known about the experiences of terminally ill people of working age.

We carried out a survey **of over 1,000 HR professionals** to identify policies and practices currently in place designed to support employees working with a terminal illness diagnosis.

We issued **a 'Call for Practice'** to curate practice examples from organisations and communities of care which offer support to people with a terminal illness diagnosis who want to continue to work.

HEADLINE RECOMMENDATIONS

- **National policy:** review employment legislation to ensure appropriate safeguards, reasonable adjustments and support are in place to protect terminally ill workers.

- **Nationally:** prepare guidance on minimum standards and good practice for large, medium-sized and small employers, across all industries and sectors.

- **Employers:** HR professionals, in collaboration with occupational health services where possible, should develop an effective framework to support employees with a terminal diagnosis.

- **In place:** integrated care partnerships and economic forums should understand the needs of working age people with a terminal diagnosis in their area, and articulate how these will be met and disparities reduced. This should be addressed in integrated care strategies and workplace wellbeing charters and accreditation programmes.

- **Research:** Future studies should specifically explore personal motivations to work in the context of a limited life expectancy; understanding how and why experiences at work for people with terminal illness vary. The effectiveness of interventions for supporting employees with a terminal illness should also be reviewed to understand what works, for who, and in what contexts.

More detailed recommendations are presented on page 14.

BACKGROUND

There is evidence of strong bi-directional links between wellbeing and employment: being employed can improve your wellbeing, and having good wellbeing can make it easier to work. However, people of working age who have been diagnosed with a terminal illness, and those who care for them, often find themselves forced to leave their employment[1].

In addition to the distress of dealing with a terminal illness, individual and household financial wellbeing can be significantly impacted by declining health, barriers to accessing welfare support and challenges to maintain paid employment in a flexible manner[2]. In the UK, around 25,000 people a year of working age die whilst in poverty[3]. There is very little information available about the number of working age people living with a terminal illness and the employment policies and practices designed to support them.

[1] Kochovska, S., Luckett, T., Agar, M. and Phillips, J.L., 2018. Impacts on employment, finances, and lifestyle for working age people facing an expected premature death: a systematic review. Palliative & Supportive Care, 16(3), pp.347-364.
[2] Marie Curie (2019) The cost of dying: The financial impact of terminal
[3] Marie Curie (2022) Dying in poverty: Exploring poverty at the end of life in the UK.

The scoping review methodology:

1. Identify the research question: "What research has been carried out on the experience of terminal illness in working age people?"
2. Identify relevant studies through extensive database and grey literature searches.
3. Select the studies (see 'Making the cut').
4. Chart the data.
5. Collate, summarise and report the results.
6. Consult with stakeholders.

Making the cut

Inclusion criteria:

- Studies involving individuals of working age who were terminally ill and reported on activities and experiences related to work.
- Original research of any study design (including quantitative, qualitative, and mixed methods approaches).
- Reports from grey literature and research which were not peer-reviewed.

Exclusion criteria:

- Studies which did not specify a terminal illness.
- Studies reporting solely on experiences of carers and health professionals.
- Studies reporting solely on activities and experiences not related to work.
- Studies which were not written in English.

Figure 1 summarises the primary reason for exclusion and the flow of studies through the identification and screening process.
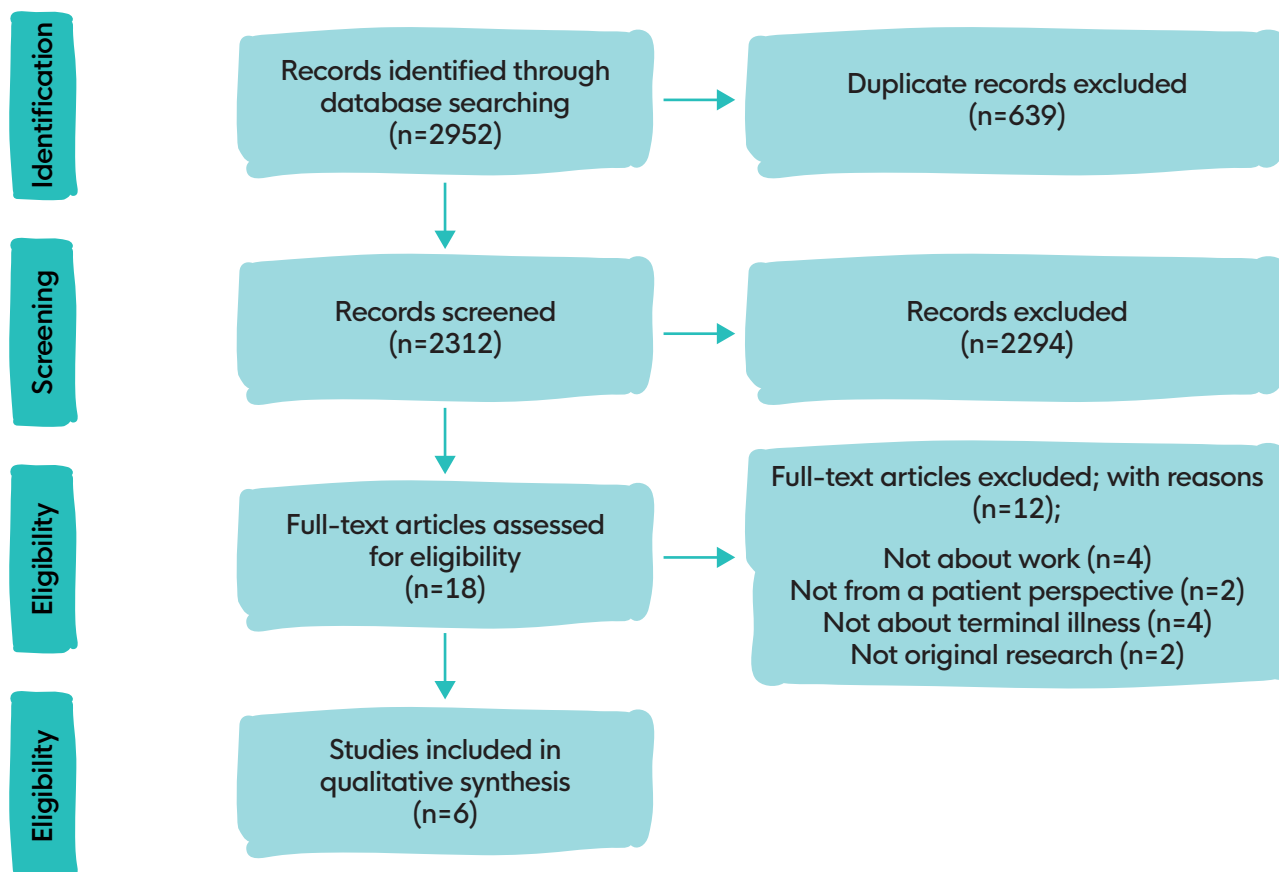

Identification

Records identified through database searching (n=2952) → Duplicate records excluded (n=639)

Screening

Records screened (n=2312) → Records excluded (n=2294)

Eligibility

Full-text articles assessed for eligibility (n=18) → Full-text articles excluded; with reasons (n=12);

Not about work (n=4)
Not from a patient perspective (n=2)
Not about terminal illness (n=4)
Not original research (n=2)

Eligibility

Studies included in qualitative synthesis (n=6)

Fig.1 – flow of studies through the identification and screening process

Three of the papers focused on the financial and economic impacts of terminal illness. Two investigated antecedents and predictors of continuing work. The final study explored the experience of everyday legal needs towards the end of life. Three studies employed qualitative research methods and three quantitativemethods. Study participants had a range of diagnoses including cancer, amyotrophic lateral sclerosis, Chronic Obstructive Pulmonary Disease (COPD), and muscular dystrophy. Only one study was published in the last five years; and three are over ten years old. Each paper was assessed for quality using the Mixed Methods Appraisal Tool (MMAT)[3].

The six included studies are summarised in Table 1:

Reference	Aim	Sample Size	Country	Quality
Financial and economic impacts				
Cagle et al., 2016	Establish an understanding of the drivers of financial burden at the end of life.	n=176	USA	Moderate
Essue et al., 2015	Measure sources of financial stress, the extent of economic hardship, and explore the factors that contribute to economic hardship	n=30	Australia	High
Emanuel et al., 2010	Explore the economic impact of terminal illness on families and on the feasibility of training caregivers as a method of stemming illness-related poverty.	n=11	India	Moderate
Factors affecting decisions to work				
Oechsle et al., 2011	To analyse the impact of physical activity and self-instructed training in patients with incurable malignancies undergoing palliative chemotherapy on an outpatient basis on the quality of life and subjective physical well-being.	n=53	Germany	Moderate
Westaby et al., 2005	Intentions to work during terminal illness: an exploratory study of antecedent conditions	n=125	USA	Moderate
Legal needs				
Close et al., 2021	To investigate the nature, impact and management of legal needs in the context of end of life care	n=14	UK	High

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[3] Hong QN, Pluye P, Bujold M, et al. (2017) Convergent and sequential synthesis designs: implications for conducting and reporting systematic reviews of qualitative and quantitative evidence. Syst Rev 6(1): 61

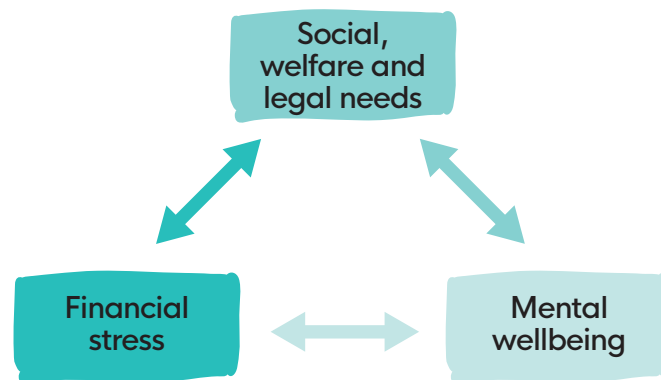Three core and inter-related themes were identified:

Fig. 2 – identified themes

As a direct result of being diagnosed with a terminal illness, participants experienced financial stress which was partially related to unmet legal needs, both of which caused disturbances to mental wellbeing.

A separate theme of **factors affecting continuation of work** was also observed.

1. Social welfare legal needs

People reported difficulties in:

- Accessing the support they were entitled to, for example applying for benefits.
- Meeting legal needs including writing a will and preparing a lasting power of attorney.
- Making funeral preparations.

This was due to:

- Lack of awareness of what was available.
- Encountering complicated processes and procedures for navigating information when applying for support.
- Feeling unable to address legal needs as there were too many other things to worry about, such as immediate financial issues, or feeling psychologically unprepared to begin making end of life arrangements.
- High costs of making a will or assigning power of attorney and feeling like this was not within their budget or worth the expense.

It was easier when:

- Healthcare professionals and key workers provided direct support to complete and, in some cases, submit paperwork on their behalf, for example applying for a permit badge to park in disabled parking spaces.
- People were supported to engage with preparing wills and advance care planning as this was experienced as a largely positive exercise that provided peace of mind and relieved pressure from family members.
- People had existing personal contacts with professional legal experience able to provide information, support, and advice on legal rights.

2. Financial Stress

People experienced financial stress due to combination of:

- a sudden loss in household income from the patient stopping work;
- partners reducing their working hours to fulfil caring responsibilities; and
- an increase in expenses such as fuel and parking costs (required as public transport gradually became inaccessible), prescriptions and mobility aids.

Financial strain was more common when the person with terminal illness was a man, from an ethnic minority group, or did not have health insurance.

Efforts to manage financial stress led to families:

- using up savings that were originally intended for retirement;
- remortgaging their homes;
- borrowing money.

Studies identified damaging consequences for the carer, often a spouse, and the household in the long-term.

3. Mental Wellbeing

Mental wellbeing was not directly assessed or measured by any study included in this review. There were several references to psychological distress, not necessarily caused by the illness but resulting from having to manage complex personal, financial and legal challenges at an already difficult time. Participants identified stress and anxiety, experiencing depression and sleep disturbances as a result.

4. Factors affecting continuation of work

One study explored the reasons people with a terminal illness had for working. It found those motivated by personal enjoyment, purpose and passion were more likely to continue working compared to those driven solely by financial reward.

Measuring wellbeing

In the six studies, four categories of measures were used:

- employment, income, and finance;
- physical health;
- health care;
- psychological.

Although the ONS4 measures of personal subjective wellbeing were not measured in any of the identified studies, one study asked: "Do you have something to look forward to each day?", "Do you have a strong will to live?" and "Do you find meaning in your life?" using a 3-point response format (1=no, 2=uncertain, 3=yes). This closely aligns with the ONS4 measure of purpose and meaning.

Conclusions from the scoping review

There is **very limited evidence available** about experiences and wellbeing related to work among people of working age who have a terminal illness. This review found only six studies which reported relevant information, with very few exploring the role of work and the workplace directly. Only one of the six studies included any details about employment status or information about the workplace, and only one study took place in the UK. No studies focused specifically on the wellbeing of people of working age.

The findings indicate that **people of working age experience significant financial and legal challenges as a direct result of terminal illness.** This can interact with challenges of their diagnosis and compound the poor mental wellbeing of individuals and their close family members.

We found evidence that **factors unique to this age group, such as loss of family income, cost of childcare, and mortgage and rent costs, may cause additional strain** compared to older populations. We found evidence that the financial stress experienced by this group of people can vary depending on individual characteristics which suggests inequalities by gender, ethnicity, and costs of healthcare.

There was **little exploration of the benefits to mental wellbeing gained by continuing to participate in work.** This could impact wellbeing via financial security, positive relationships with colleagues, or through personal satisfaction, sense of identity, enjoyment and a sense of purpose. When exploring the range of quantitative measures used to assess health at the end of life, there were several objective and subjective measures of physical health and health care used, but very **little focus on emotions, mental health, and wellbeing.**

Since the conception of this review, there have been two significant changes in policy which will impact the wellbeing of those diagnosed with a terminal illness:

- The Social Security (Special Rules for End of Life) Bill which allows people in the UK who are at the end of life to receive support if they are thought to have a life expectancy of 12 months or less, replacing the previous threshold of 6 months life expectancy; and
- The Health and Care Bill which is a change in law requiring palliative care services in every area of England.

These recent policy changes, as demonstrated by this review, are sorely needed, and indicate continued interest and concerted efforts towards sustaining wellbeing at the end of life.
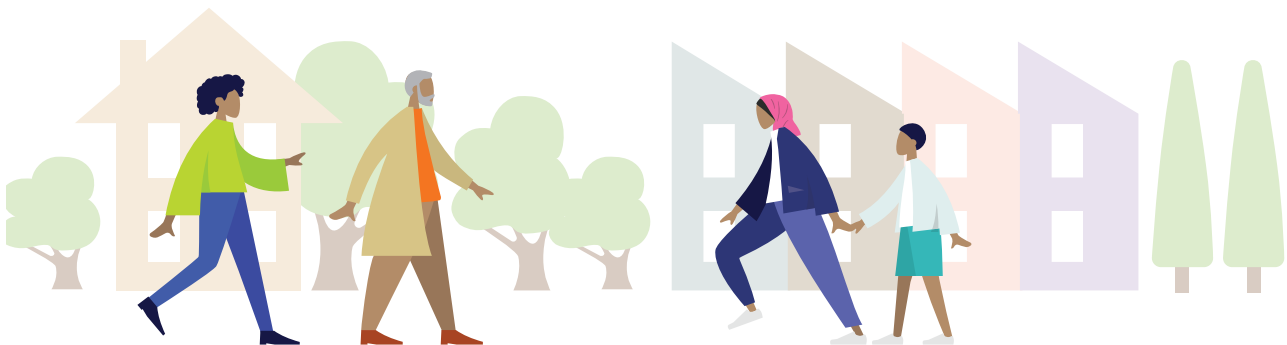
To understand more about existing workplace support and practices for employees working with a terminal illness, we commissioned an online survey of HR decision makers. Survey data was collected and analysed by YouGov Plc. Fieldwork took place from 11th - 30th August 2022. 1,016 HR decision-makers responded. This included staff across small (10-49 employees, 53%), medium (50-249 employees, 25%) and large (250+ employees, 22%).

Experience of supporting employees with a terminal illness diagnosis

To the best of your knowledge, has your organisation ever supported an employee with a terminal diagnosis?

- Yes, it has
- No, it has not
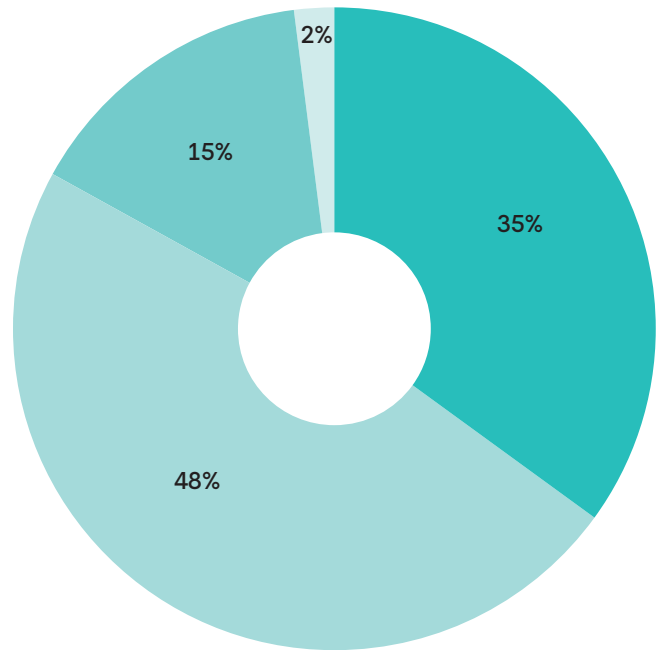- Don't know, don't recall
- Prefer not to say

Fig. 3 - support organisations provide to employees with terminal illness

How are terminally ill employees supported in the workplace?

When asked to describe how their organisation supports terminally ill employees, over a third replied that they did not know. One in ten didn't answer the question. From those who did provide a response, a small number commented that it was not their place: "We don't actively get involved as an employer". Another respondent reflected that terminal illness was not considered different to any other illness employees might encounter during their working lives: "It does not. Not beyond any other illness type."

In contrast, many HR professionals described an organisational approach shaped by compassion, flexibility and sensitivity: "We have a holistic approach. Working with the member of staff and their families" and "With compassion and maintained employment". More detailed responses underlined the importance of tailoring support and responding to their employees' needs: "We tend to be guided by the person who is ill. It's very important to us that we do whatever we can to remove some of the worry and help in whatever way we can so we discuss the options and hopefully come up with a plan that appeals."

Where organisations did provide support, six areas were identified:

1. **Attendance and flexible working:** "We try to give support with regard to flexible working and time off for appointments."

2. **Managing sickness and absence flexibility:** "We waive our usual sick pay rules and pay them company sick pay for an indefinite period."

3. **Work adjustments:** "Will issue tasks to be completed from home, or other more comfortable environments for as long as the employee wishes."
"We have let people step down from senior roles without decreasing their base pay to give them less stress."

4. **Occupational health and employee assistance programmes:** "Support helpline provided as part of benefits package." "We offer an employee assistance programme for advice and counselling."

5. **Insurance policies:** "Permanent Health Insurance & Death in Service cover which pays on diagnosis of a terminal illness." "We provide income protection plans to provide them with an income if they are unable to work."

6. **Direct financial support:** "We may pay for taxi fares for hospital appointments." "We offer an added bonus to their annual pay to help cover costs." "Can write off certain expenses to the company."

The most common support provided by companies was flexible working, work adjustments and paid time off. Less than half of companies managed an employee's terminal illness outside of standard sickness reporting processes. Encouragingly, 17% of respondents expressed an interest in learning more about putting this procedure in place.

Support/provision to employees

Does your organisation offer any of the following support/provision for employees living with terminal illness? (please select the option that best applies on each row)
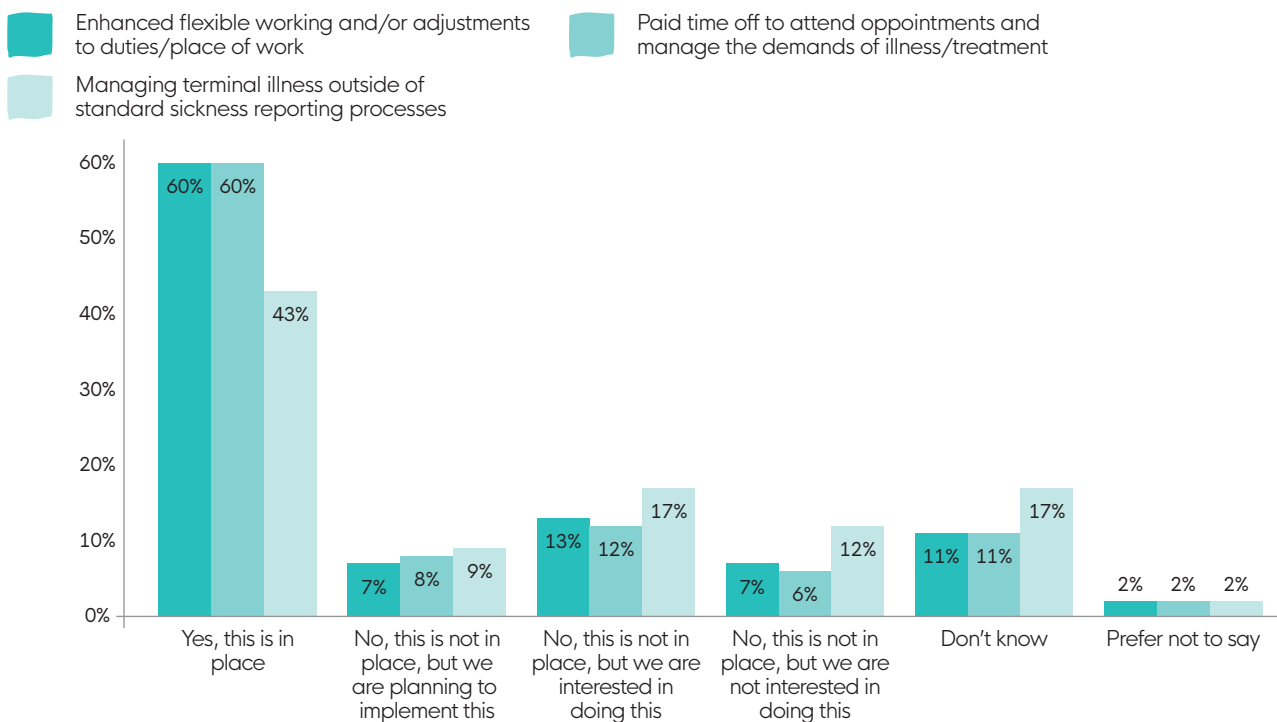

Fig. 4 – support organisations provide to employees with terminal illness

Just over a third of companies had guidance for line managers on how to manage and support employees with a terminal illness, and 22% were interested in putting this in place.

Organisation wide Support/provision

Does your organisation offer any of the following company wide support/provisions?
(please select the option that best applies on each row)

- **(teal)** Guidance for line managers on how to support staff diagnosed with a terminal illness
- **(light teal)** Tailored Occupational Health terminal illness support
- **(medium teal)** Signposting to sources of support and information (e.g. financial advice, advance care planning, Employee Assistance Programme and external sources such as Marie Curie, Macmillan etc)
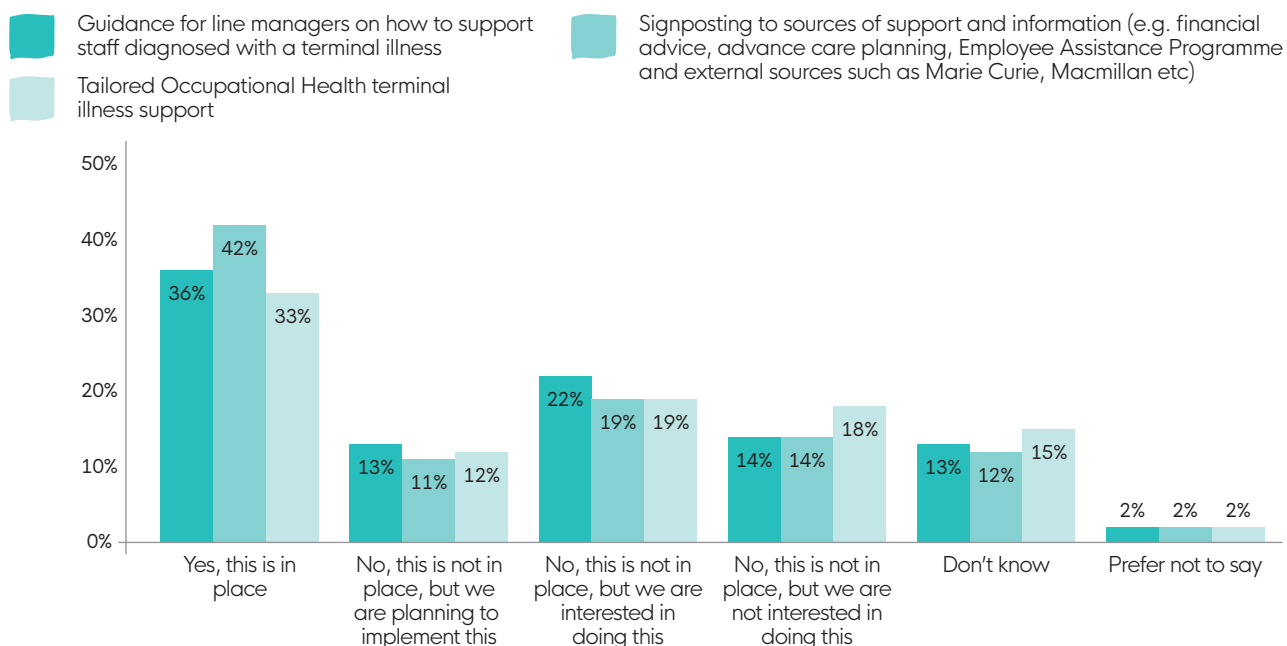

Fig. 5 - organisation wide provision

TUC Dying to Work Charter

Organisations who sign the TUC Dying to Work Charter commit to ensuring employees will be understood, supported, protected and guided throughout their employment, following a terminal diagnosis. Signatories pledge:

1. To manage employees with terminal illness with support and understanding.

2. That employees with a terminal illness will not be dismissed because of their condition.

3. To provide safe and reasonable work, recognising it can help maintain dignity, offer a valuable distraction and be therapeutic in of itself.

4. To recognise that employees have the right to choose the best course of action for themselves and their families which maintains dignity and eliminates undue financial loss.

5. Death in service benefits will be protected.

Hull City Council: prioritising financial wellbeing

A signatory of the TUC's Dying to Work Charter, Hull City Council applied the charter's principles to prioritise the financial wellbeing of a terminally ill employee. They swiftly removed barriers so that the employee could access their pension entitlement, providing a level of financial security and enabling their employee to spend their remaining time with family.

West Northamptonshire Council: flexible working and policy discretion

The Council supported an employee who wished to continue working following a terminal diagnosis. They applied existing policies and procedures flexibly and made reasonable adjustments. This allowed the individual to work from home whilst receiving treatment. The Council also applied discretion in the application of their sickness absence policy, extending sick pay and reducing the hours worked when the employee was medically signed off as not fit to work. This avoided triggering the Council's sickness absence review procedure, and provided assurance to the employee that their reduced attendance would not be considered grounds for dismissal.

How common are policies for terminally ill employees?

Overall, almost half of HR decision makers said their organisation had policies in place for terminally ill employees (44%). Two thirds of these policies formed part of a wider company policy (68%); the rest were stand-alone policies (32%).

Formal support

Does your organisation have formal practices established regarding employees diagnosed with terminal illness?
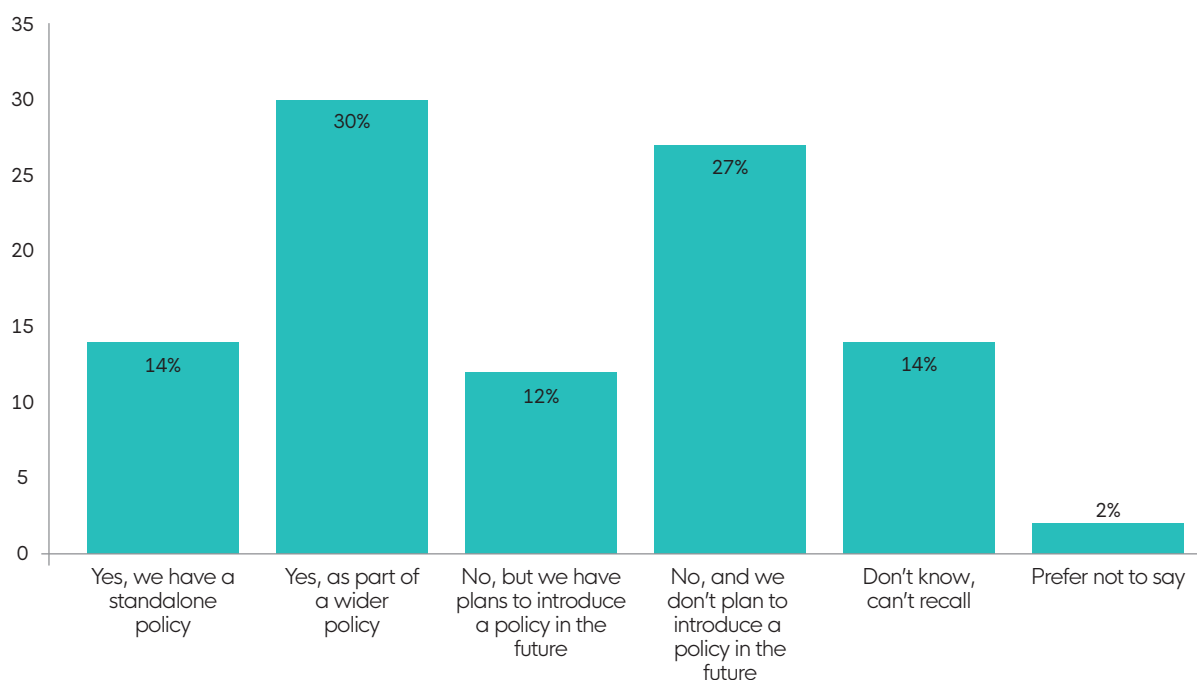

Fig. 6 - the extent to which organisations have formal practices for terminal illness

Companies without policies were asked if they had any plans in place to create such policies and most (69%) said that they had no such plans. It was significantly more common for larger companies to have policies for terminally ill employees.

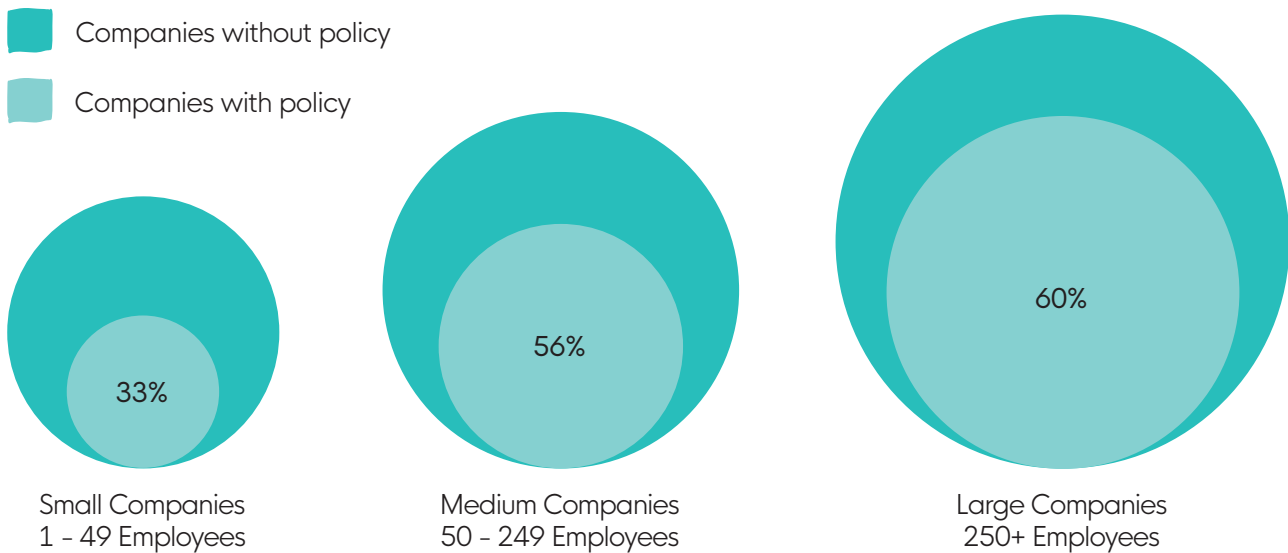## Rates of having Terminal Illness Policies by Company Size

- ● Companies without policy
- ● Companies with policy

| Small Companies
1 – 49 Employees | Medium Companies
50 – 249 Employees | Large Companies
250+ Employees |

33%   56%   60%

Fig. 7 – rates of Terminal Illness policy by company size

The survey also revealed differences in presence of terminal illness policies across industry sectors. Policies were **more common in companies within the financing and accounting industry (51%) as well as the IT and telecoms industry (56%).** Policies were less likely to be in place in companies in the hospitality and leisure (27%) .

What makes the biggest difference?

HR decision makers were asked what they thought would make the biggest difference to improving the work experience of people living with terminal illness who would like to keep working. Flexible working, and organisation/team culture were the most frequently cited approaches.

Offering flexibility: "Treating individuals on a case by case basis. Not all illnesses are the same so until you know the situation it is very hard to judge. Ensuring staff feel safe at work if they want to be there and are supported in treatment and time off and not made to feel like it is an inconvenience."

Creating an open, inclusive and supportive culture: "Continuing to treat them as valuable within the workplace with an understanding of any changes they need put in place to enable them to continue to contribute." "Creating safe spaces for people to freely talk."

Having sensitive and supportive conversations: "Listening and taking into account the individual's bespoke needs." "Not being afraid to talk about it with them and find out what would help them." "Reducing stigma and encouraging conversations."

Nottinghamshire Fire and Rescue Service: autonomy and control

The Fire Service supported a terminally ill trainee firefighter to achieve their ambition of completing training and working a shift. Although the individual's employment was short, they were entitled to death in service benefits from their employer as well as financial support from the Fire Brigade Union. The employer was able to provide meaning and purpose to an individual who wished to continue working beyond business need, and ensure they were able to make choices in how their employment proceeded.

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Oxford University: work and identity

A college supported their Head Chef to continue in work following a stage 4 cancer diagnosis. This involved time off for treatment and flexible working. Further medical leave was sensitively negotiated, after which the employee chose to retire on grounds of ill health. No longer able to access the college's electronic bulletin boards, or receive college emails, and due to pandemic restrictions, the employee lost contact with close colleagues and updates on college life. This led to the employee feeling both a loss of identity and reduced social connection. The employee died during covid restrictions, so colleagues were unable to attend his funeral. When restrictions were lifted, the college organised a memorial for friends and family, hosted in the college, where colleagues were able to gather, pay their respects and commemorate his life.

Conclusions from the survey of HR decision makers

Over a third of the 1,000 HR professionals surveyed worked in organisations where they had supported an employee with terminal illness. Almost half of organisations had established formal practices to guide this support. There was significant variation depending on organisation size and industry sector. The most frequently provided support was flexible working, work adjustments and paid time off. Less than half of companies managed an employee's terminal illness outside of standard sickness reporting procedures.

There is an 'employer lottery' in which the support people receive, and their access to it, varies significantly. This had the greatest impact on employees of small companies, which are also the least likely to have policies in place. In some cases, this 'employer lottery' is further compounded by value judgements, which could, in the absence of published procedures, lead to unjust and avoidable inequity in support.

The employer lottery

"We will review pay on an ad hoc basis"

"It would be at the discretion of the Senior Management Team"

"Depends on situation and employee level"

"In reality it varies in ways that reflect their status"

"Depends on who or what but probably can't support greatly"

"It hasn't got a formal process. It's ad hoc"

The survey responses highlight the value of having policies and procedures in place to guide early discussions, and the importance of a trusted, compassionate workplace culture. HR Professionals identified improved guidance and training resources, greater awareness of signposting opportunities, and receiving direct financial support from the government, would most likely improve their organisation's capability and performance in this important area.

For national policy

Protection for employees with a terminal diagnosis

Review existing legislation to ensure appropriate safeguards, reasonable adjustments and support are in place to protect terminally ill workers. This includes requiring employers to take steps to **avoid both dismissal on grounds related to an employee's terminal illness and reducing salary** after an employee has had a period of sickness absence with shifts from occupational to statutory sick pay.

Flexibility in statutory sick pay

Recent revisions to the Special Rules for Terminal Illness will make it quicker, simpler and easier for people approaching the end of their lives to claim benefits. Offering **greater flexibility in the payment of statutory sick pay**, for example reviewing eligibility criteria in relation to terminal illness and making provision for phased returns, would enable employees approaching the end of their lives, and their employers to support them to stay in work and mitigate financial loss.

Minimum standards and good practice guidance

While many employees receive excellent support from their employer upon receiving a terminal diagnosis, our research suggests the support provided, and an employee's opportunity to access this, varies significantly. Guidance is needed on **minimum standards and good practice** for large, medium-sized and small employers, and those self-employed across all industries and sectors.

Supporting smaller organisations

Our research suggests that small and medium-sized employers are least prepared to support an employee receiving a terminal diagnosis, and have least access to support they can offer employees. Options for **building capacity and capability in smaller organisations** to support employees working with a terminal diagnosis should be explored.

Access to legal and financial information

There is an urgent need to improve and streamline access to legal and financial information for people with terminal illness. This could be achieved through formal **incorporation of legal and financial health checks in the workplace**. Specific considerations will have to be made to account for the different types of employment and workplaces e.g., self-employed to ensure equity in access to support.

For working at scale, in place

Placemaking strategies

Although the employment contract is an agreement between individual employee and employer, there are **opportunities to develop placed-based approaches to supporting workforce health and wellbeing** that would build capacity and capability across and between organisations. This could be particularly valuable for smaller organisations. **Workforce sections of new Integrated Care Strategies** and the needs assessments that inform these should use this evidence from research and practice to enhance their understanding of workforce health and wellbeing and identify disparities. Strategies should **articulate how the needs of working age people with a terminal diagnosis will be met and disparities reduced.**

Economic partnerships

Many regions now have workplace wellbeing partnerships and accreditation schemes that recognise the efforts of employers in addressing health & wellbeing in the workplace. Examples include Thrive at Work West Midlands Combined Authority or the Mayor of London's Good Work Standard. These partnerships could act as conveners for discussions in place - **collaboratively developing frameworks and guidelines** to support employers, line managers and employees diagnosed with a terminal illness. This could include curating local resources for information, advice and guidance.

For employers

Policy and Procedures

Our research identified that less than half of organisations had policies in place detailing the approach and support employees with a terminal illness can expect from their employer. **HR professionals, in collaboration with occupational health services where possible, should develop an effective framework to support employees with a terminal diagnosis**. This should be integrated within the organisation's wider health and wellbeing framework and link to appropriate support. **They should ensure line managers understand the organisation's framework** for managing and supporting employees with a terminal diagnosis in regard to:

- Attendance and flexible working
- Managing sickness and absence
- Work adjustments
- Occupational health and employee assistance programmes
- Insurance policies
- Direct financial support

Where practical, this should be developed into a standalone policy or form part of broader HR policy, and health and wellbeing frameworks.

Line manager capability

Creating an open, inclusive and supportive culture where managers are confident and capable to provide compassionate and practical support for an employee with a terminal diagnosis is essential. A line manager's behaviour and the culture they create in their team is a major influence on an employee's work experience. This is especially true for employees working with a terminal diagnosis who will need not only support but empathetic and sensitive understanding. Organisations should **ensure that managers have the skills, knowledge and access to relevant information** to effectively support employees with a terminal illness.

Leaving work with dignity

At some point, it is probable that an individual with a terminal diagnosis will decide they need to stop working. If work has been a major focus in an employee's life, this can be difficult to adjust to emotionally and financially. Employers should **explore ways to support the employee leave the organisation with dignity**. This could include a compassionate approach to others taking over an individual's duties, and helping the individual to maintain supportive workplace friendships.

Wider workforce wellbeing

If an employee dies during employment, there can be a significant impact on their close colleagues and across teams. The organisation and line managers should **be prepared to provide compassionate bereavement support** for those affected by the loss and grieving.

Evaluating impact

Our review failed to identify any research on the effectiveness of interventions to support employee wellbeing for those working with a terminal illness. Organisations should **evaluate the impact of their interventions to support people** and engage with their employees to understand how they can best support people.

For commissioners of research and researchers

Motivation to work with terminal illness

Future studies should specifically **explore personal motivations to work in the context of a limited life expectancy**, focussing on the role of work in personal identity, purpose and meaning in life, personal enjoyment, social connections, and autonomy, in addition to financial motivations. It is important to determine where the experience is positive or negative, what factors are significant to improve wellbeing, and how these vary depending on the employment sector and type of work being undertaken.

Experience of work with terminal illness

On a structural level, research should aim to understand: **how and why experiences at work for people with terminal illness varies** depending on the diagnosis; the economic impact of supporting people with terminal illness to continue work; how often employers are required to support an employee with a terminal illness, and training and support needs of employers.

Variation in access to support

On a societal level, future research should further explore the **inequalities in access** to legal support, experience of financial strain, and the impact of terminal illness on mental wellbeing.

Measuring what matters

A **conceptual review of wellbeing at the end of life** would inform the use of existing measures and, if required, support the development of new instruments.

Effective workplace policy

Future research should seek to **establish what good looks like** in a workplace policy for supporting employees with a terminal illness. The **effectiveness of interventions** should also be reviewed to understand what works, for who, and in what contexts.

For healthcare professionals and key workers

After being diagnosed with a terminal illness employees may receive care and support from a number of health and social care professionals. These individuals can support an employee through decisions relating to carrying on working, changing the type or amount of work or stopping working either for a short time or permanently. In some cases, it may be appropriate for healthcare professionals to act as a bridge between an employee and an employer HR department. There is also an important role in supporting individuals to meet their social, legal and welfare needs, financial wellbeing and emotional support.

ACKNOWLEDGEMENTS

Clair Fisher 1979-2022

This research was conceived in partnership with Clair Fisher, a long-time collaborator of the What Works Centre for Wellbeing. Clair was diagnosed with stage 4 bowel cancer in 2018. Throughout her treatment and palliative care, it mattered to her that the time she had was good. Dying Well was Clair's retirement project; a space for her to document her personal journey, to explore the evidence around wellbeing in terminal illness and test out some of the theories. One of Clair's missions was to make it easier for terminally ill people to keep working while they want to.

This research is one of the many lasting contributions she has made towards this aim.

In partnership with

Marie Curie

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