

Working with terminal illness

What is known and
what is needed

Joanne Smithson
Head of Implementation
& Learning



Survey of HR Decision Makers

- What is their experience?
- What support does their organization provide?
- What would most likely improve the experience?



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 decisionmakers responded.

Across sizes and sectors

small (10-49 employees, 53%)

medium (50-249 employees, 25%)

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

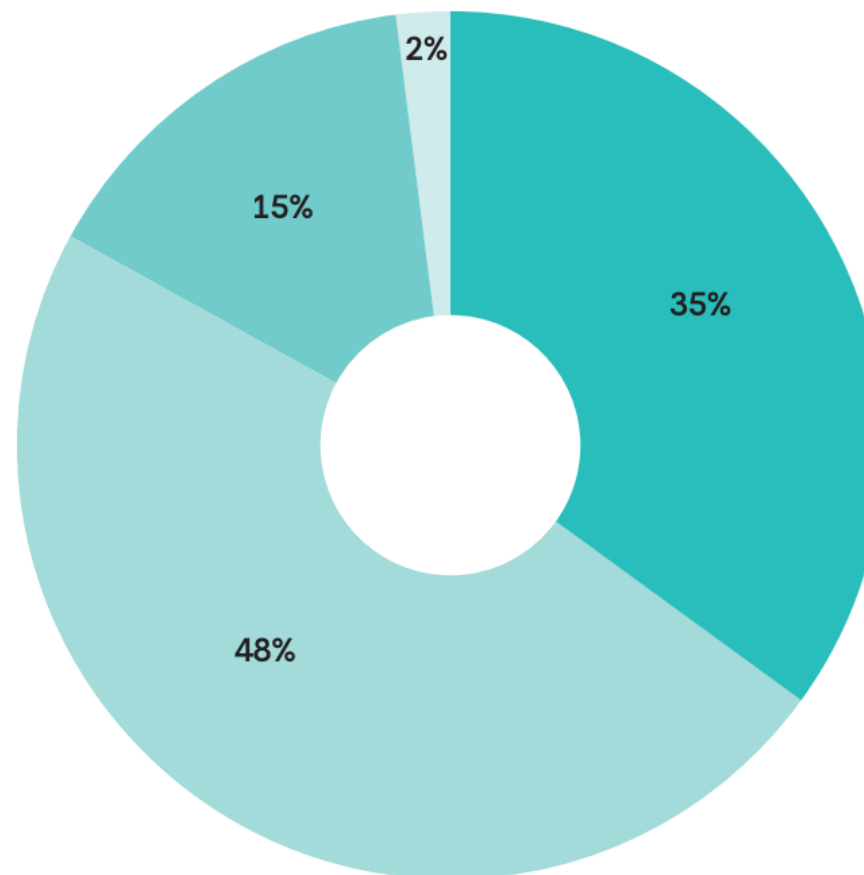


Fig. 3 - support organisations provide to employees with terminal illness

How are terminally ill employees supported in your workplace?



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- One in three did not know
- One in ten didn't answer the question




How are terminally ill employees supported in the workplace?

- 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 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.”

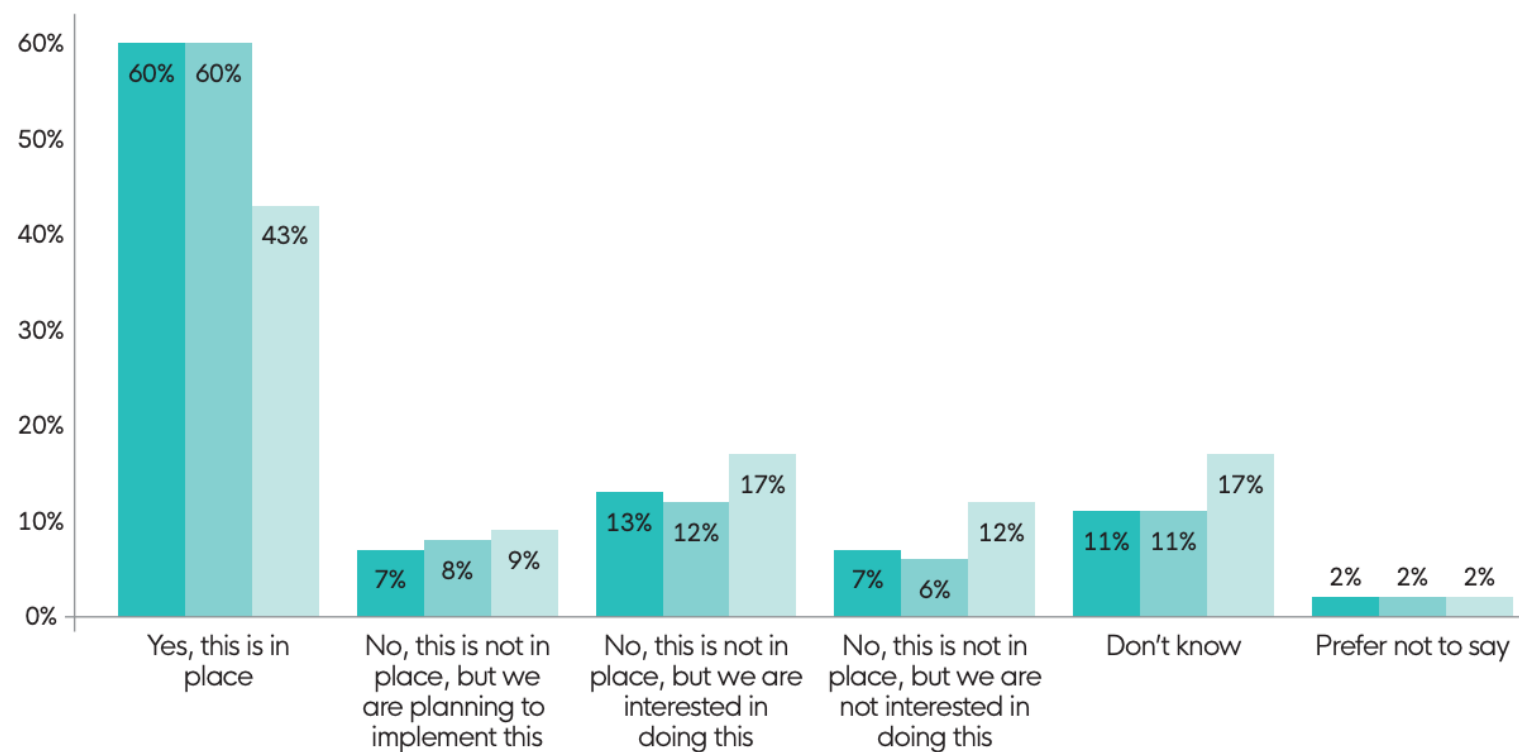
Support/provision to employees

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)

 Enhanced flexible working and/or adjustments to duties/place of work

 Paid time off to attend appointments and manage the demands of illness/treatment

 Managing terminal illness outside of standard sickness reporting processes

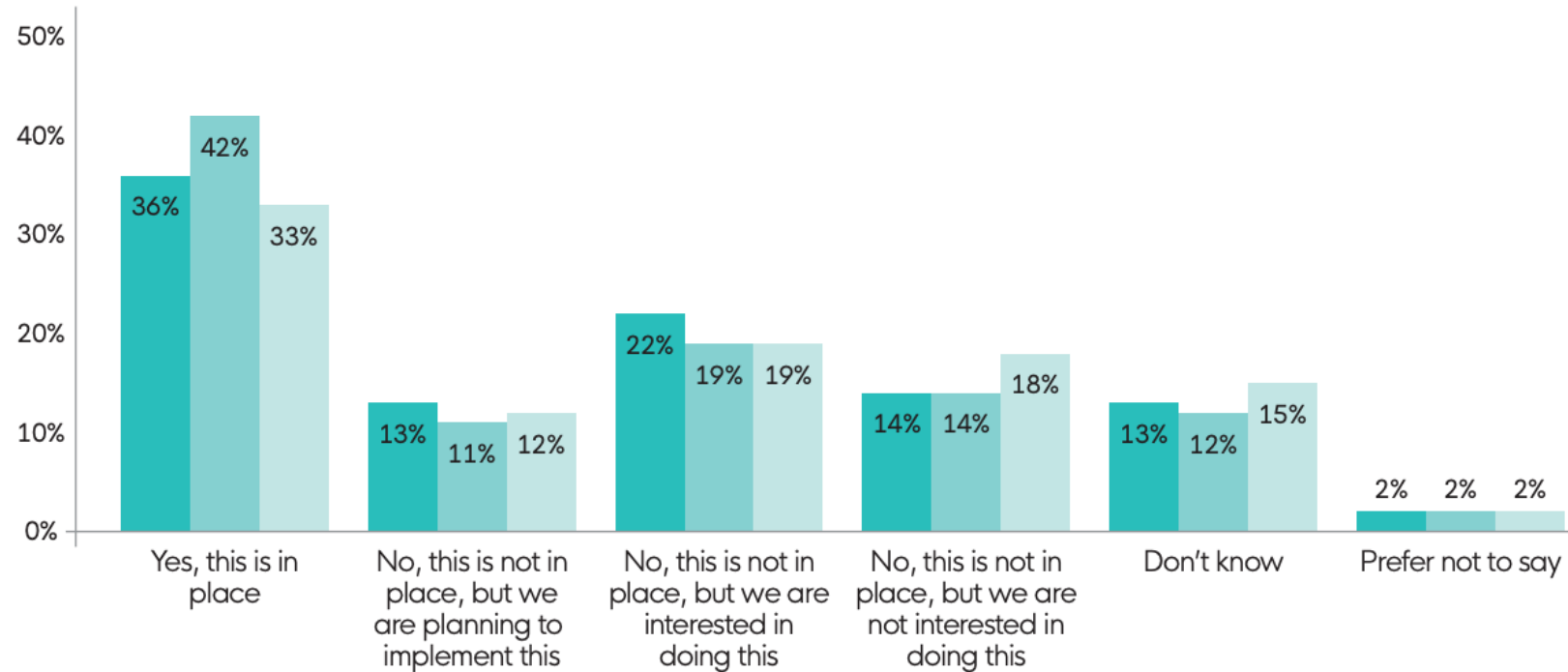


Organisation wide Support/provision

Does your organisation offer any of the following company wide support/provisions?

(please select the option that best applies on each row)

- Guidance for line managers on how to support staff diagnosed with a terminal illness
- 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)
- Tailored Occupational Health terminal illness support

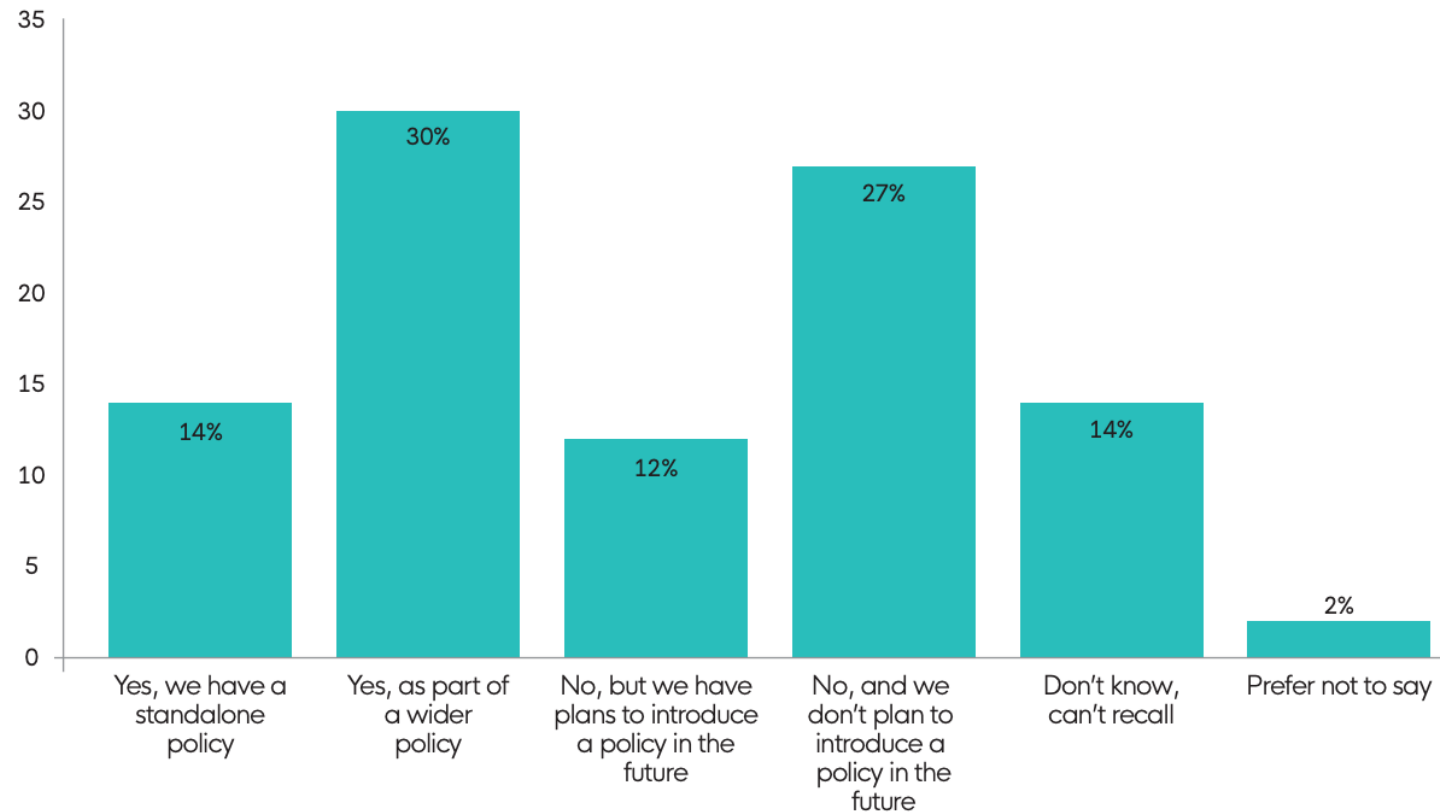


How common are policies for terminally ill employees?

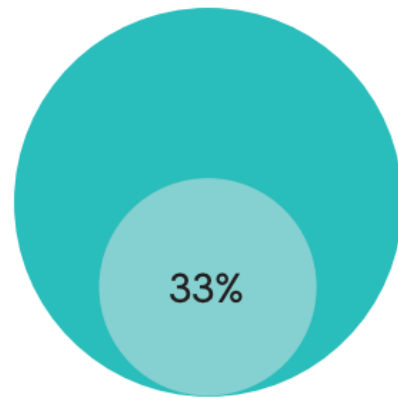
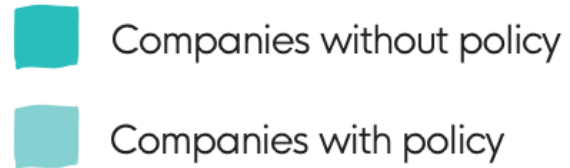
Overall, almost half of HR decision makers said their organisation had policies in place for terminally ill employees (44%). Two thirds of these policies formed part of a wider company policy (68%); the rest were stand-alone policies (32%).

Formal support

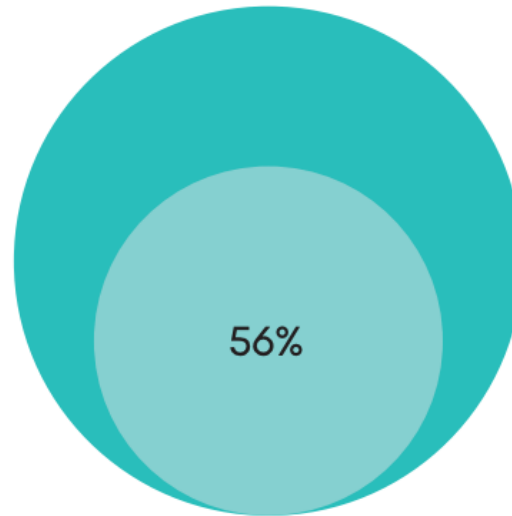
Does your organisation have formal practices established regarding employees diagnosed with terminal illness?



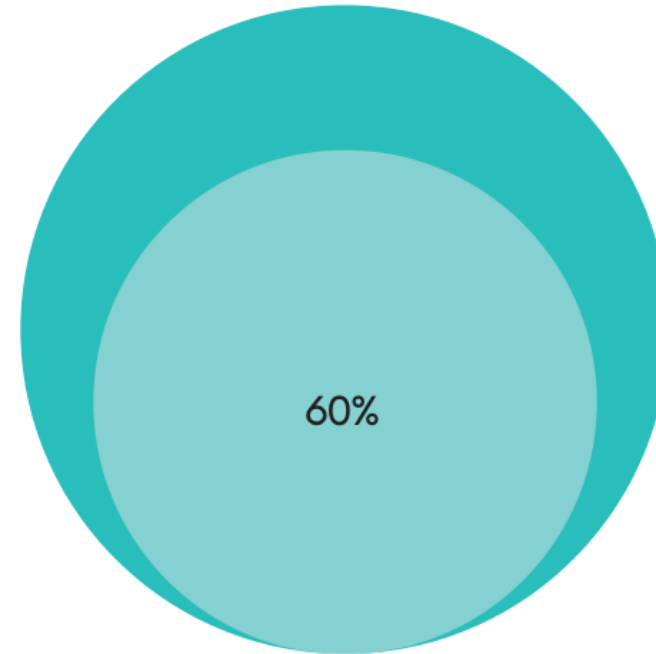
Rates of having Terminal Illness Policies by Company Size



Small Companies
1 - 49 Employees



Medium Companies
50 - 249 Employees



Large Companies
250+ Employees

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."

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"

Recommendations



For national policy

- Protection for employees with a terminal diagnosis
- Flexibility in statutory sick pay
- Minimum standards and good practice guidance
- Supporting smaller organisations
- Access to legal and financial information

- Placemaking strategies
- Economic partnerships

GOOD WORK PLEDGE ✓



For employers

- Policy and Procedures
- Line manager capability
- Leaving work with dignity
- Wider workforce wellbeing
- Evaluating impact – what works?

For commissioners of research & researchers

- Motivation to work with terminal illness
- Experience of work with terminal illness
- Variation in access to support
- Measuring what matters
- Effective workplace policies

For healthcare professionals and key workers

- The team around the employee and their family & close contacts
- Decision support
- Social, legal and welfare needs

Reflections

1. What is the relevance of this review and its findings to your work and/or sector?
2. What are the themes or interventions that you think we can progress?
3. What opportunities exist in your networks to progress?



THANK YOU!

