

# Dying in Poverty in Northern Ireland 2024





## Introduction

**E**VERYONE diagnosed with a terminal illness should be given financial security. Marie Curie has been raising awareness of the prevalence, risk factors and impact of poverty at end life for people affected by terminal illness. We have also been outlining evidence-based policy solutions to address these issues. This report provides an update on poverty rates since 2019 – following nearly two years of high inflation. We’ve previously reported on the vulnerability of people living with a terminal illness to energy costs,<sup>1</sup> and this report also estimates the number of people who die in fuel poverty. The data modelling also found that across the UK, rates of poverty among people at the end of life were greater than among the rest of the population.<sup>2</sup>

Many people living with a terminal illness want to be cared for and die at home, surrounded by their loved ones.<sup>3</sup> It is

unacceptable that these extremely vulnerable people are experiencing acute financial difficulties such as struggling to pay their rent or mortgage, and living in cold, damp homes because they cannot afford to heat them properly.

Financial stress and living in a cold home can have an enormous impact on the mental and physical health of someone living with a terminal illness, as well as their general quality of life. This includes increasing their risk of developing mental ill health such as anxiety, depression and social isolation. It may also lead to their physical health condition deteriorating faster.

Despite the hugely welcome change to fast-track access to benefits for people living with a terminal illness under “Special Rules,” the social security system often fails to provide an effective financial safety net against people falling into poverty.

“I had visited this family a few times before this point as the father slowly declined from illness. One night we were sitting up and he was not sleeping. I asked him what was on his mind and he told me: ‘I just want to die’. I asked him why, thinking if there was pain or something else that could be managed, we could work together to solve it. Instead, he told me that he felt he was a burden, and that he didn’t know how his family was going to afford ‘all this’. I tried to reassure him by telling him that his family didn’t see it as a burden, but he replied that it didn’t matter, because he knew that his sons had taken time off work to be with him, and they had families of their own and bills to pay.”

#### Experience of Northern Ireland Marie Curie Hospice Care at Home Nurse.

This is partly because the benefit system does not adequately take account of the cost of being ill. It has been estimated that on average, a household which includes an adult living with a disability faces additional costs of around £1,000 per month specifically related their condition or disability – even after benefits have been paid.<sup>4</sup> This gap has widened during the cost of living crisis.

The Motor Neurone Disease Association has estimated that people living with MND can spend on average more than £600 a year on electricity costs for charging and using assistive equipment, on top of other additional household costs for MND.<sup>5</sup> The cost of running medical devices is not sufficiently monitored or reimbursed by any of the health systems across the UK. A recent FOI request with each of the five Health and Social Care Trusts (HSCTs) in Northern Ireland found inconsistencies in information held on patient use of medical devices in the home, and significant gaps in the financial support provided for running devices.

It’s not right in a modern society to allow people to die while struggling to heat their homes or run vital medical equipment. This report repeats recommendations made from our first report for changes to the social security system to ensure it adequately supports people living with a

terminal illness.<sup>6</sup> It also makes a number of energy-specific recommendations, including our support for the introduction of a UK-wide social tariff to better protect those most vulnerable to energy poverty.

We urge the Northern Ireland Executive and Assembly to work with Westminster, local Government and the Energy Industry, to consider the recommendations in this report and move towards a society where no-one dies in poverty.

**The main analysis for this report has been conducted by academic researchers at Loughborough University’s Centre for Research in Social Policy, using a combination of the longitudinal Understanding Society survey and mortality rates from NISRA. Further data including details on the methodological approaches applied are available from the main reports.<sup>7</sup>**

## Key findings: Northern Ireland

1. One in every five people who died in Northern Ireland in 2023 were in poverty (n=3,300), this compared to 1 in 7 in 2019 (n=2,033).
2. The number of people who died in poverty in Northern Ireland in 2023 has risen by 1,300 since 2019.
3. Poverty impacts both working-age and pension-age people at the end of life.
4. Pensioner poverty has almost doubled from 10% to 19% since 2019.
5. More than one in every four people who died in Northern Ireland in 2022 were in fuel poverty (n=4,600).
6. The increase in spending on energy for people at the end of life in Northern Ireland was much higher compared to other parts of the UK.
7. Among pension-age people in the last year of life, 27.2% died in fuel poverty in Northern Ireland and was the highest across all regions of the UK.
8. A UK-wide social tariff on energy could prevent up to 54,000 people dying in fuel poverty.

*Please note: comparison between poverty and fuel poverty rates is not possible as different metrics were used to calculate poverty and fuel poverty. The data used was also from two different years.*

**“There was a hospital bed in the centre of the room, and a very frail person was in it covered in many layers of blankets. It was far too cold in the house for the heating to have only just been turned off. I checked on my patient, who was in her last days, and she was very, very thin. I worried about the weight of all those blankets on top of her, but for now at least she had seemed comfortable so I left them alone thinking if I removed any she would easily become far too cold.”**

**Experience of a Marie Curie Nurse who cared for someone in their own home in Northern Ireland**

# The picture in Northern Ireland

## Overall poverty

The Social Metrics Commission definition of poverty has been used to estimate poverty rates, and takes account of income after “inescapable costs” have been deducted, such as housing, childcare and costs relating to disability.

More people are dying in poverty in 2023 than they were in 2019. 2,000 people a year died in poverty in Northern Ireland in 2019. Now, that number has risen to 3,300 (Table 1).

**Table 1: Estimated number/proportion of people experiencing poverty in last year of life in Northern Ireland in 2019 and 2023**

Year	Number in poverty in last year of life	Proportion in poverty in last year of life
2023	3,300	19.9%
2019	2,033	13.0%

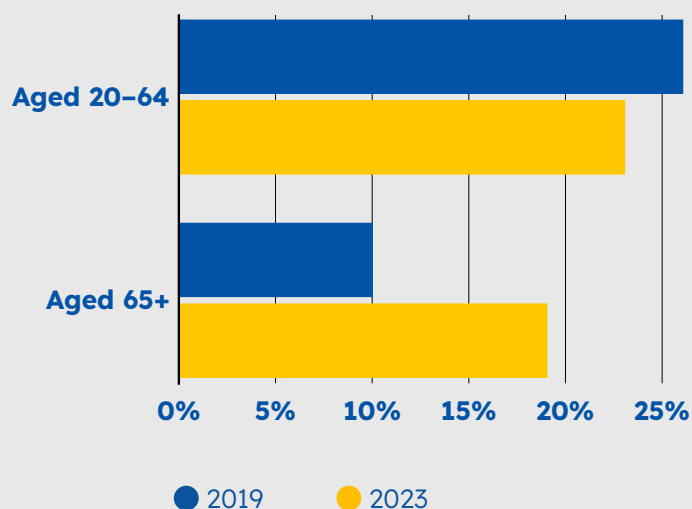
As demonstrated in Table 2, both working-age and pension-age people are impacted by poverty at end of life. Pension-age people are affected in greater numbers, and a greater proportion of working-age people are affected. Targeted action needs to be taken to address the specific risk factors and needs for both groups.

**Table 2: Estimated number/proportion of people experiencing poverty in last year of life in Northern Ireland in 2023**

Age group	Number in poverty in last year of life	Proportion in poverty in last year of life
20-64	800	23.3%
65+	2,500	19%
<b>Total</b>	<b>3,300</b>	<b>19.9%</b>

It's very concerning that the statistics for Northern Ireland show that pensioner poverty has almost doubled from 10% to 19% since 2019, while working-age poverty has seen a slight decrease over the same period (Figure 1, page 6). This increase in pensioner-age poverty is also apparent in council level statistics where levels have increased by between 6 and 10% (Table 3, page 6).

One explanation for this stark increase in pensioner poverty may be because the age categories used to compare poverty rates no longer completely differentiate those eligible for their state pension (20-64 and 65+), as this has increased to 66 years. Those aged 65, who are now only eligible for working-age benefits rather than the more generous State Pension, could potentially be contributing to the rise in the poverty rate for this age group.

**Figure 1: Proportion of people dying in poverty in 2019 and 2023****Table 3: Proportion of pension-age people dying in poverty between 2019 and 2023**

Local authority name	Last year of life			
	2023 percentage	2023 number	2019 percentage	Percentage point increase
Derry City and Strabane	21.9%	217	11.6%	10.3%
Fermanagh and Omagh	19.7%	159	10.0%	9.7%
Causeway Coast and Glens	18.7%	205	9.9%	8.8%
Newry, Mourne and Down	18.8%	233	10.1%	8.7%
Belfast	20.8%	509	12.2%	8.6%
Mid Ulster	18.3%	174	9.8%	8.5%
Armagh City, Banbridge and Craigavon	18.0%	243	10.0%	8.0%
Mid and East Antrim	16.5%	186	9.6%	6.9%
Antrim and Newtownabbey	16.3%	167	9.6%	6.7%
Ards and North Down	16.0%	229	9.4%	6.6%
Lisburn and Castlereagh	15.0%	168	9.5%	5.5%

## Fuel poverty

Fuel poverty means having inadequate income to heat or power your home.

Factors affecting fuel poverty include:

- living in poorly insulated housing
- expensive energy tariffs
- increased energy need
- living on an inadequate income.

Energy costs can rise significantly at the end of life due to factors such as the need to power medical equipment or store medicines safely, increased time spent at home and corresponding higher fuel usage, and increased need to maintain a particular body temperature.

Nations within the UK use different measures for fuel poverty. For this report, the Scottish measure has been used, which is defined as: Fuel costs to maintain a satisfactory heating regime are over 10% of the household's income after housing costs, and after housing, fuel, disability, and childcare costs, the remaining income is less than 90% of the Minimum Income Standard (MIS).<sup>8</sup>

This measure of fuel poverty does not identify people who should be spending more than this but go without (either by simply not turning the heating on or "self-disconnecting" by not topping up their prepayment meter). So, the figures in this section are lower bounds for the numbers of people who die in fuel poverty.

More than one in every four people who died in Northern Ireland in 2022 were in fuel poverty (Table 4).

**Table 4: Estimated number/proportion of people experiencing fuel poverty in last year of life in Northern Ireland in 2022**

Year	Number in fuel poverty in last year of life	Proportion in fuel poverty in last year of life
20-64	800	23.8%
66+	3,800	27.2%
<b>Total</b>	<b>4,600</b>	<b>26.5%</b>

Among pension-age people, the rate of fuel poverty in the last year of life was higher in Northern Ireland compared to any other part of the UK, where 27.2% were estimated to die in fuel poverty. London was the next highest region (25.6%), and the South East of England had the lowest rate of fuel poverty in last year of life (16.3%).

Table 5 (page 8) shows the proportion of working-age people and pensioners estimated to have died in fuel poverty. It shows a significant percentage of working-age and pension-age people experience fuel poverty at end of life, however pensioners and those living in Derry City and Strabane, as well as Belfast, appear to be most impacted.

**Table 5: Proportion of working-age people and pensioners dying in fuel poverty in 2022 (by council)**

Council	Percentage of working-age people who died in fuel poverty	Number	Percentage of pensioners who died in fuel poverty	Number
Derry City and Strabane	27.1%	121	30.8%	778
Belfast	26.8%	323	30.5%	1,906
Causeway Coast and Glens	24.6%	90	27.6%	772
Newry, Mourne and Down	23.7%	110	26.4%	832
Fermanagh and Omagh	23.5%	71	26.2%	539
Armagh City, Banbridge and Craigavon	22.7%	138	25.1%	863
Mid and East Antrim	22.6%	75	25.0%	720
Ards and North Down	22.5%	88	24.8%	907
Mid Ulster	22.4%	76	24.7%	598
Antrim and Newtownabbey	21.4%	78	23.3%	614
Lisburn and Castlereagh	20.2%	71	21.9%	627

### **Inequalities in fuel poverty rates at end of life**

Across the UK, there's an increased risk of fuel poverty among certain groups of people who are at end of life. In many cases, some people may fall into more than one risk group. These findings underscore the need to understand and address these disparities:

- people living with a non-cancer diagnosis (21%) compared to those with a cancer diagnosis (18%)
- those living in social and private rented (46%; 32%) compared to homeowners (11%)
- those from a minoritised ethnic household (27%) compared to a white household (19%)
- the impact of sex is more nuanced with working-age men (22%) and pension-age women (22%) at a similar risk of fuel poverty.

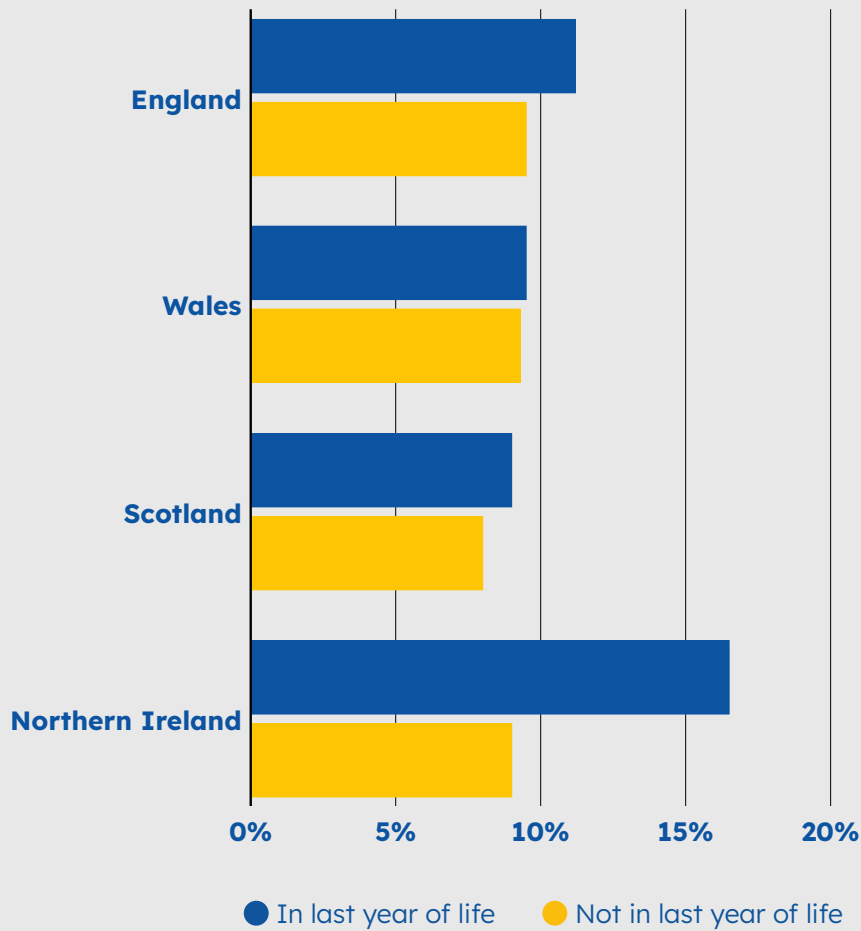
### **Spending on energy**

Overall, people at the end of life saw their energy spend increase more than households not at the end of life across each nation of the UK. The period covered by this analysis was a time of rising prices, so energy spending increased for households regardless of whether they are in the last year of their life.

However, as shown in Figure 2 (page 9), the increase in spending on energy was particularly high for people at the end of life in Northern Ireland. This is very concerning and the reason for the difference is unclear. However, the statistics also show higher rate of spending on oil compared to other fuel types, such as gas or electricity. Nearly half of homes in Northern Ireland rely on oil for heating (49.5% in 2021), which is significantly higher than any other part of the UK.<sup>9</sup> There are no price caps on oil and the prices can fluctuate quite considerably.



**Figure 2: Percentage change in annual spending on energy by nation between 2021-22**



For this reason, it’s possible that households with people at end of life may have stockpiled oil due to concerns about prices rising further, although it is less clear why they would have done so to a greater extent than households not at the end of life.

**Self-disconnection**

In the analysis, the only way to identify who has fuel costs necessary to maintain a satisfactory heating regime of over 10% of their income was to look at who *actually* spends that much. That means this measure of fuel does not identify people who should be spending more but go without. For this reason, the figures in this section likely underestimate the number of people who die in fuel poverty.

The risk of under-consumption of energy exists for people with low income and/or high energy need, regardless of payment type. However, this risk is greater for prepayment meter or heating oil customers, as this can be forced (by the meter having no credit or the supply of oil having run out), whereas a credit customer is not constrained in this way. Prepayment meters for electricity and gas are common in Northern Ireland and usage rates are increasing year on year. In Northern Ireland, 47% of households have a prepayment meter for electricity and 69% have a gas prepayment meter.<sup>10</sup>

The energy market has indicated that they have no way of identifying people who have self-disconnected and that the introduction of smart meters will make this easier.

All energy providers are required to have Customer Care Registers which hold details of the special needs of customers who are of pensionable age, living with a disability or chronically sick. Currently, the energy market relies on people self-identifying as having a long-term illness or disability. Unfortunately, domestic customer surveys indicate very low awareness and sign-up rates for these registers.

Measures to address poverty more generally, through ensuring an adequate income to pay for essentials, can improve ability to afford fuel. However, there are also particular measures that can, and should, be taken to provide support for fuel costs specifically.

The Utility Regulator has a number of commitments under their Consumer Protection Programme that focus on practice improvements in the energy market. This includes monitoring compliance with the code of practice on consumers in vulnerable circumstances and reviewing the energy supplier codes of practice on prepayment meters and payment of bills in 2025/26.

### **Identification and targeting of support**

Identification and targeting of support to highly vulnerable consumers, such as people living with a terminal illness, is not only an issue for energy companies, but a challenge for government and charities, too. The Special Rules system which expedites access to social security benefits for people living with terminal illness is a valuable source of information. However, it only includes people who have less than 12 months or less to live and is only used for purposes of benefit entitlements. The overall consequence of lack of data sharing is that the onus is placed on the dying person or their family to repeatedly inform different organisations of their condition, which in turn raises the risk that information and support does not reach everyone that needs it.

### **Emergency and long-term energy cost support plans**

Measures to improve the energy efficiency of homes can reduce energy bills, however, such work can take time and be disruptive. Both factors mean that they are not likely to be suitable for people approaching the end of their lives, and so more immediate forms of support are needed alongside improving energy efficiency, which will deliver benefits to people at the end of their lives in future years.

There are two annual government-administered energy support grants: the Winter Fuel Payment and Cold Weather Payment. Neither provide guaranteed support to someone living with a terminal illness and both have very restrictive eligibility criteria. In fact, the criteria for the Winter Fuel Payment has been tightened further, moving from a universal pension benefit to a means-tested pension benefit. There are also substantial regional disparities in access to energy support grants across the UK. The Warm Home Discount scheme that is available in Great Britain is funded and administered by the energy market and does not extend to Northern Ireland. Factors that make an extension to this service difficult could be that Northern Ireland is a much smaller marketplace, with a higher proportion of customers still using oil.

Energy support grants in Northern Ireland are generally short-term, released on a first come-first-served basis rather than being targeted, and available funds are capped rather than based on anticipated need. In the longer term, we need to move away from one-off support payments and towards a social security system that allows people living with a terminal illness to be assured a stable income that will help them to maintain a basic standard of living which recognises the costs directly attributable to their illness.

**Table 6: Potential impact of introducing a UK social tariff on fuel poverty at the end of life**

	<b>In fuel poverty</b>	<b>Still in fuel poverty with a social tariff</b>	<b>Potential reduction in fuel poverty from a social tariff</b>
Working-age	18,000	13,500	4,500 (25%)
Pension-age	110,000	60,690	49,310 (45%)

Figures in Table 6 are UK-wide estimates.

In terms of domestic energy costs specifically, Marie Curie also supports the call for a social tariff system which would offer a more sustainable solution by providing financial support for the households who need it most.

### **Energy social tariff**

Analysis conducted by Loughborough University has indicated that a UK-wide social tariff that provided certain households with a 50% discount on their energy bill could lift as many as 54,000 people out of fuel poverty at the end of life in the UK, and could come close to halving rates of fuel poverty among pension-age people at the end of life (Table 6). It is also notable that even with a significant social tariff

discount and no behaviour change, at least 74,000 people in the UK would not be lifted out of fuel poverty at the end of their life, because their current energy usage is more than 20% of their income. A solution which would take the pressure off the many households using oil as a home heating fuel would also need to be considered. This demonstrates both the urgent need for significant action to address fuel poverty, and that a social tariff would need to be combined with other measures to end fuel poverty at the end of life.

# Conclusions and recommendations

**T**HIS report has shown that poverty rates at end of life have increased substantially since 2019, affecting people of both working and pension age. The report has also shone a light on the scale of fuel poverty, specifically among people at the end of life. It has identified factors that increase risk, such as type of disease, ethnic background, sex and housing status, and that these inequalities must be addressed.

The issues raised in this briefing deserve serious consideration and action by both Westminster and the Northern Ireland Executive, Assembly and local government. People at the end of life deserve to spend their final days making memories with family and friends rather than worrying about paying bills, living in a cold home, or leaving their relatives with unmanageable debt.

It is concerning that while the situation has worsened in terms of poverty rates at end of life, this report also repeats many of the calls made in our 2019 report. It is now time to act. We have made multiple recommendations below, but two key actions that would have the greatest impact are a guarantee of a pension-level income for those of working age living with a terminal illness, and the introduction of a social tariff for energy bills.

Future strategies to address poverty, such as the Anti-Poverty Strategy and the Fuel Poverty Strategy must also ensure that the needs of people living with a terminal illness are considered in all planned measures. More broadly, Northern Ireland desperately needs an updated Palliative

and End of Life Strategy which can take a long-term, holistic view of the needs of people living with a terminal illness.

People with a terminal illness do not have the luxury of time – we must act now.

## Recommendations

**Recommendation 1:** The UK and devolved governments should work together to improve the identification, recording, and sharing of information about people living with a terminal illness, both in the last 12 months of life and with longer prognoses.

**Recommendation 2:** The Northern Ireland Government should work with the Westminster Government to ensure that the social security system adequately supports people living with a terminal illness. This includes giving people of working age early access to the State Pension, and introducing the self-care element to Universal Credit to replace the Severe Disability Premium.<sup>11</sup>

**Recommendation 3:** Provide additional support with the cost of childcare to all parents living with a terminal illness.

**Recommendation 4:** Better support carers by introducing a Carer Allowance Supplement in Northern Ireland and increasing the value of carer element of Universal Credit.

**Recommendation 5:** The Northern Ireland Government should engage with the Department for Energy Security and Net Zero on the potential of a social tariff for energy scheme.

**Recommendation 6:** The Northern Ireland Government should ensure that people living with a terminal illness are able to access emergency financial support with the cost of energy. This should include exploring ways to provide people in Northern Ireland with an equivalent to the Warm Home Discount.

**Recommendation 7:** The Northern Ireland Government should engage with the Westminster Government to review eligibility for the Winter Fuel Payment. The Winter Fuel Payment should be offered to everyone diagnosed with a terminal illness, regardless of age or whether they receive Pension Credit or another means-tested benefit.

**Recommendation 8:** NHS trusts should record and report information on the number of patients in their area who are using medical devices at home. The UK and devolved governments should use this to introduce an upfront rebate scheme for the use of all at-home medical devices.

**Recommendation 9:** All relevant bodies should ensure they have plans in place to minimise winter deaths and the health impacts of cold homes or fuel poverty, particularly in relation to terminal illness, and that this is incorporated into care plans. This includes implementation of NICE guideline NG6.

**Recommendation 10:** The Utility Regulator in Northern Ireland should take account of the specific needs of people living with a terminal illness when setting standards and monitoring supplier practices. This should include actively monitoring supplier compliance with licence conditions around self disconnection, review of appropriateness of prepayment meters, and actions to improve uptake of customer care registers.

# References

1. The Vicious Cycle of Fuel Poverty and Terminal Illness
2. Further detailed data is available from the Centre for Research and Policy, Loughborough University. <https://www.mariecurie.org.uk/policy/poverty>
3. Public Attitudes to Death, Dying and Bereavement in the UK revisited (2024)
4. <https://www.scope.org.uk/campaigns/disability-price-tag>
5. Through The Roof, MND Association
6. Poverty at the end of life
7. <https://www.mariecurie.org.uk/policy/poverty>
8. Unlike the NI definition, it avoids classifying high-use but high-income households as being in fuel poverty by considering households post-energy income. Unlike the England definition, it does not require someone to live in an energy-inefficient household to be considered in fuel poverty.
9. <https://researchbriefings.files.parliament.uk/documents/CBP-9838/CBP-9838.pdf>
10. Utility Regulator NI – Consumer Insight Tracker 2023
11. A more detailed explanation of these benefit recommendations are available in the full UK Report. <https://www.mariecurie.org.uk/policy/poverty>

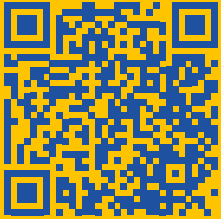
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For the full report and recommendations visit:



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