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Comparison of financial support for carers of people at the end of life across six countries: a descriptive study

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Abstract

Background: Family caregivers of people at the end of life can face significant financial burden. Whilst appropriate financial support can reduce the burden for family caregivers, little is known about the range and adequacy of financial support, welfare and benefits for family caregivers across countries with similarly developed healthcare systems.

Aim: To identify and compare sources of financial support for family caregivers of people approaching the end of life, across six countries with similarly performing healthcare systems (Australia, Canada, Ireland, New Zealand, United Kingdom and United States of America).

Design: A survey of financial support, welfare and benefits for end of life family caregivers was completed by 99 palliative care experts from the six countries. Grey literature searches and academic database searches were also conducted. Comparative analyses of all data sources documented financial support within and between each country.

Results: Some form of financial support for family caregivers is available in all six countries, however the type, extent and reach of support varies. Financial support is administered by multiple agencies, eligibility criteria for receiving support are numerous and complex, and there is considerable inequity in the provision of support.

Conclusion: Numerous barriers exist to the receipt of financial support, welfare and benefits. We identified several areas of concern including a lack of clarity around eligibility, inconsistent implementation, complexity in process and limited support for working carers. Nonetheless, there is significant potential for policymakers to learn from other countries experiences, particularly with regard to the scope and operationalization of financial support.

What is already known about the topic?

- The costs of family caregiving for people at the end of life can be substantial, and financial burden can have a range of negative consequences for carers
- Family caregivers report difficulties accessing benefits and financial support.
- Countries differ in how financial support is implemented and operationalised.

What this paper adds

- Our study summarises the financial support, benefits and welfare that are available to end of life caregivers in Australia, Canada, Ireland, New Zealand, United Kingdom (UK) and United States of America (USA).
- We outline some of the barriers to uptake of financial support including complex eligibility criteria and applications, inconsistent implementation and lack of support for working carers.

Implications for practice, theory or policy

- There is significant potential for policymakers to learn from other countries experiences, particularly with regard to the scope and operationalization of financial support.
- Consideration should be given to the adequacy of current financial support, particularly with regard to working carers, and how to achieve equitable uptake.

Keywords: family caregivers; informal caregivers; carers; palliative care; end of life care; financial burden; costs

Word count = 3199

Introduction

Family caregivers represent the foundation of the palliative care workforce and are the main providers of end of life care. [1] It is estimated that family caregivers provide 75%–90% of home-based care for people who are near the end of life. [2] However, caregivers often feel unsupported in their role [3], which impacts on their ability to continue caring. [4] A recent Eurobarometer survey explored preferences regarding government contributions to helping carers. Financial remuneration for caregiving was considered to be the most important support for family carers. [5] Research from the USA, Australia and New Zealand has also reported the substantial financial disadvantage associated with caregiving at the end of life [6, 7, 8]

A systematic review of family caregiver costs in palliative care reported that the financial costs of caring for someone at the end of life are substantial. Financial costs can result in significant caregiver burden including difficulties coping, family conflict and major life changes such as moving house and changing employment [9]. Little support is available to help in managing costs, but the potential impact of failing to support carers financially is catastrophic, given their crucial role in providing palliative care and reducing reliance on statutory services. Whilst data are sparse, family caregiver costs are believed to represent a significant proportion of the overall costs of healthcare at the end of life. A study from Canada reported that 26.6% of the total cost of care in the last 5 months of life was borne by family caregivers. [10] More recently, Chai et al. (2014) found that over the last 12 months of life, unpaid caregiving costs accounted for 77% of total palliative care expenses. [11]

Whilst financial information and support do exist, family caregivers report difficulties understanding eligibility for benefits and navigating complex application systems whilst juggling the demands of caregiving. [12] Moreover, whilst there is increasing recognition within government policies of the contribution of family carers, financial support often comes with a trade off in terms of restrictions on employment, further limiting opportunities for managing financial burden. [1] At national level, concerns about how best to support family caregivers have featured on the political agenda of a number of countries in recent years. [13] However, when it comes to services designed to support family caregivers financially, only limited evidence is available. There is a particular lack of evidence on the availability and suitability of financial support available for end of life caregivers. [14] This is despite evidence which suggests the urgency of the end of life context can increase the financial demands of caregiving. [8]

Most countries with high performing health systems do provide some financial support for caregivers. [13] However, comparative research across countries with similarly performing health systems is sparse regarding the different financial supports available. [15] The possibility for policymakers to learn from other countries' experiences is therefore limited. The aim of this study is to identify and compare sources of financial support available directly or indirectly for family caregivers of people approaching the end of life, across six countries with similarly performing healthcare systems. This mapping exercise will provide an overview of the arrangements in place in a complex and evolving policy area, with a view to sharing learning between and within countries.

Methods

In the context of this study we define ‘family caregiver’ as those who may or may not be family members, but who are lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotional management. [16]

Selection of countries

We sought to include countries that display similar characteristics regarding both health system and level of palliative care development. Countries were selected with the highest performing health systems (Health Access and Quality Index score in the top two deciles) [17], and those with preliminary or advanced integration of palliative care (level 4a/4b according to the Global Atlas of Palliative Care). [18] Due to a lack of translation facilities our choice of countries was limited to those where data could be extracted in English. The countries selected were: Australia, Canada, Ireland, New Zealand, United Kingdom (UK) and United States of America (USA).

Design

There are inherent difficulties in capturing comprehensive data on financial support, welfare and benefits as these data are not collated anywhere at a regional, national or international level. Therefore we chose a design incorporating four complementary phases, based on the methods described by Beek et al. (2013) [15] and Courtin et al. (2014). [13] Firstly, we developed a survey comprising an inventory of financial support, welfare and benefits for caregivers of those approaching the end of life. The inventory attempted to capture both direct (aimed at the family carer) and indirect (aimed at the patient but which benefits the family carer) sources of financial support. Individual items in the inventory were developed from research on services for family caregivers [19] and sources of financial burden for family caregivers. [6,8] Free text options were also included to allow additional context to be provided. The final inventory comprising 13 items was piloted with two palliative care academics recruited through an existing research network, and minor changes were made to wording to aid clarity.

Patients, carers and experts in palliative care policy, service delivery, advocacy and research from each of the six countries were invited to complete the inventory. Participants were identified using convenience sampling through existing informal networks and formal collaborations (e.g. International Palliative Care Family Carer Research Collaboration). Survey respondents were asked to identify additional participants from their country and recruitment was thus progressed using snowball sampling. Participants were sent a link to complete the survey via e-mail, and responses were automatically recorded using Google Forms. Consent was presumed if a response was submitted.

The second phase involved comprehensive grey literature searches of each country. The purpose of the literature review was to confirm, extend and add to the findings generated from the expert survey. Grey literature searches focused on government agencies, palliative care/carer organisations and charities in the six countries. Keywords were used to direct searches and were developed from survey responses and scoping (search strategies are provided in supplementary file 1) Thirdly, internet databases Medline and PubMed were searched for original research containing information about financial support for carers in the participating countries, using the same keywords and related MeSH headings. Potentially relevant literature from the grey literature and academic databases was screened by CG and BT to ensure it met inclusion criteria (listed in table 1), any disagreements were resolved through discussion. All relevant literature was extracted onto a predefined proforma capturing key aspects of financial support. Further details of the search strategy can be found in supplementary file 1.

Finally, a comparative analysis was performed of the survey responses and the associated literature. This involved populating a summary table for each country (table 6), with data derived from survey

responses and from the literature reviews. Data were organised according to the type and scope of financial support, the focus (patient or carer) and any eligibility criteria. To ensure data were accurate and comprehensive for each country we sent the summary tables to an expert 'checker' from each of the countries for final feedback, which was then incorporated. Data collection took place between January and July 2018.

[Table 1 about here]

Results

We contacted 105 organisations and 33 individuals and received a total of 99 survey responses. No incomplete surveys were returned. Survey respondents included clinicians (medical, nursing and allied health professionals) (41%), patients and carers (17%), government workers (local government/council or national/federal government) (15%), researchers (10%), employed in the voluntary sector (e.g. advisors for charities) (8%), volunteer or in unpaid advocacy roles (9%). Responses ranged from six (USA) to 28 (New Zealand) from each country.

All countries have an existing or planned national strategy for family caregivers (table 6). The USA has no existing strategy, however a 2017 Act passed in the House of Representatives commits to the establishment and maintenance of a Family Caregiving Strategy. The UK, New Zealand, Australia, Canada and Ireland have existing or planned palliative care strategies. The USA is notable for its lack of national strategy or policy in palliative care. The findings indicated that financial support for carers was available across all six countries in four main areas: support for the time investment required by carers; employment related rights and support; support for out of pocket costs; support with costs related to healthcare.

Financial support for the time investment required by carers

All six countries provide government funded financial support for people with significant disability, including those with terminal illness or limited life expectancy (see table 2). This support may indirectly benefit carers or in some cases be used by carers. Direct financial support for family carers is more variable but is provided as a government benefit in Australia, Canada, Ireland, New Zealand and the UK. Carer benefits are dependent on various eligibility criteria including number of hours spent caring, income, employment status and relationship with the patient. Canada is the only country which provides a payment specifically for end of life family caregivers. The Canadian Compassionate Care Benefit (CCB) is paid to working carers (at 55% of earnings) who have to be away from work temporarily to care for a family member with less than six months to live. All countries provide some form of bereavement payment or support with paying funeral costs but there is huge variation in provision. The majority of these payments are means tested or dependent on the financial status of the deceased or the caregiver.

In general, eligibility criteria vary widely and applications are complex. Survey respondents indicated that navigating such applications could put people off applying, with one hospital clinician from New Zealand noting *"There are a number of criteria that a person and their caregiver need to satisfy for any support to be offered financially, it is not universal and many do not qualify"*. Similarly from the USA a hospital clinician/academic stated *"There are numerous constraints and requirements for any of the benefits listed here"*.

[Table 2 about here]

Employment related rights and support

Support related to employment is much more variable between countries and is not always enforced at a national level or as a legal requirement (table 3). In Ireland, Canada the UK and the USA carers can take time away from work to provide care and their employment will be protected by law, however there are various caveats such as minimum service requirements, terminology which is open to interpretation (e.g. entitled to a 'reasonable' amount of time off in the UK) and certain categories of employers being exempt. In some countries employment protection for carers is not a legal requirement but is left to the discretion of employers, for example in New Zealand employees have a legal right to request flexible working to provide care but this does not have to be granted. Tax and pension benefits are similarly variable, there are a myriad of schemes that are potentially available to the cared for person and sometimes the carer, but eligibility criteria are numerous and complex.

[Table 3 about here]

Support for out of pocket costs

Support for out of pocket costs is provided to some extent in all six countries, however none provide comprehensive coverage (see table 4). For example, assistance with travel and accommodation is available, but generally only in countries with large rural or remote populations where residents have to travel long distances to access healthcare (e.g. Australia, Canada & New Zealand). Even in these cases patients must meet certain conditions to qualify e.g. a minimum distance travelled, low income. In addition the travel of a carer is not always included and they may have to cover their own travel and/or accommodation costs.

In cases of extreme financial hardship, charitable grant funding may help supplement a patient or carer's income. Grants are provided by a range of charitable organisations, however cancer charities are most prominent. In the USA, a survey participant described how carers have to resort to charity to address even their most basic needs "*Soup kitchens and food banks provide food to those in need in some areas*". In general, support for out of pocket costs appears ad hoc, difficult to access and reflects considerable inequity in financial support. For example, a carer from Ireland suggested "*rural based caregivers are neglected*" and a hospice clinician from New Zealand stated "*there are different levels of support for people of different cultures*".

[Table 4 about here]

Support for costs related to healthcare

All countries provide some financial support to help with costs related to the healthcare of the cared for person, but the nature and extent of this support varies widely (table 5). Underpinning the requirement for support with healthcare costs is the healthcare system within which each country operates. In the UK and Canada where the vast majority of healthcare is free at the point of access, there is no financial support to assist with the costs of healthcare. However in other countries where payments or co-payments are required for healthcare, various systems have been put in place to provide a safety net for those most vulnerable in society. The USA operates a comprehensive

Medicare/Medicaid Hospice Benefit scheme which provides coverage for most healthcare usage and drug costs for those in need of palliative care. However in order to be eligible patients must rescind any curative care. In Australia, New Zealand and Ireland where publicly funded healthcare provision is combined with user subsidies, those who have exceptionally high usage of services can be eligible for free or reduced services. However, some payments are generally still required and free services may be limited with one not for profit manager from Australia noting “*respite home care is very limited and many carers miss out*”.

[table 5 about here]

Discussion

This study provides an overview of the financial support that is available, both directly and indirectly, to end of life family caregivers across six countries. Whilst the majority of countries have national policies for family caregivers and palliative care, these policy commitments have failed to translate into comprehensive financial support structures for family caregivers. Whilst financial support services do exist across the six countries there are numerous barriers to receipt of these. Eligibility criteria are varied and complex, application processes are long and difficult to negotiate, benefits often come with trade-offs in terms of restrictions on employment and many benefits are means tested. Given this finding it is not surprising that many carers miss out on financial benefits, or do not receive benefits to which they are entitled. In Canada, a recent poll identified that 43% of caregivers are not aware that various financial benefits exist, and only 12% have ever used them. [20] This suggests a greater need for education around what benefits are available, but also highlights a more fundamental issue regarding how carers perceive themselves. A recent report from the UK reported that more than 36% of people who care for someone with cancer do not see themselves as a carer and therefore haven’t considered applying for benefits. [12] As a consequence financial support is only received by a minority of those who are eligible, a situation that persists across the countries included in this review. [12, 21, 22, 23, 24]

One area of financial support notable for a lack of clarity and consistency is employment rights and support. Carers who remain in paid work face significant challenges, and these difficulties can lead carers to give up paid work completely or make it impossible to return to employment after time spent caring. [25] Our findings suggest that employment rights for carers are vague and ill-defined, and employment protection is not always a legal requirement. Policy commitments to supporting working caregivers are stated in some countries. For example, the Canadian Carers Strategy advocates “creating flexible workplace environments that respect caregiving obligations”, however there are no legal requirements of employers to adhere to this recommendation. [26] Government commitment to supporting working carers is commendable, but needs to be backed up by employment legislation rather than relying on individual employers to adopt voluntary practices.

Our findings also point to considerable inequity in the provision of financial support. Receipt of benefits can depend on age, relationship to patient, geographical location, employment status, tax contributions and, notably, the diagnosis and prognosis of the cared for person. This reflects wider inequities in palliative care, where provision of comparable services and support for people with non-cancer diagnoses has long been an issue. [27] Our evidence suggests many financial benefits favour carers of people with cancer, and some are exclusively for cancer carers. This in combination with longer illness trajectories and increased dependency for non-cancer conditions, means financial

hardship can be significantly exacerbated for non-cancer carers. Indeed, evidence suggests that financial burden in carers of those with cardiac failure is worse than carers of those with lung cancer [28]. Policymakers should carefully examine financial support to ensure benefits are available to carers of any person approaching the end of life, and are suitably operationalised so as not to disadvantage particular diagnoses. Inequity also persists between the different countries we included in this review, and may reflect the different funding arrangements for healthcare. Whilst our data do not allow us to make any claims about the relationship between healthcare funding system and availability of financial support, they may well be related and this warrants further attention.

Very few of the financial supports we identified in this study were specific to end of life carers, with most being generic support available for any family caregiver. However, evidence suggests that carers of those approaching the end of life can incur significant additional costs, as the end of life context confers a sense of urgency and a 'now or never' attitude to financial expenditure. [8] This suggests that financial support should be increased, or at the very least expedited, for end of life caregivers. Whilst some countries 'fast track' disability payments for people with 'terminal illnesses', few offer a similar fast-tracking system for carer benefits. Indeed, there is little recognition from our data that end of life carers are entitled to any different supports than any other carers. The notable exception is the Canadian Compassionate Care Benefit (CCB) for working carers who provide care for someone with a life expectancy of six months or less. The CCB has been subject to some criticism for not living up to its full potential [29] e.g. only a small number of those who are eligible have actually received support. [30] Despite this, there is significant potential for policymakers in other countries to learn from the implementation of the CCB, as it has the potential for serving as a public health response to caregiver burden, and addressing the determinants of this burden [29].

Limitations

Whilst every attempt was made to produce a comprehensive inventory of financial support, we may have missed some supports. We recognise that this paper paints a picture of the nature of support available in 2018, and as the nature of financial support is constantly evolving findings should not be considered current beyond this date. We are aware that there may be additional generic sources of financial support or welfare that could benefit family carers however we have restricted the scope here to benefits *specifically* aimed at family carers. We only included six countries which were all English speaking and this limits generalisability.

Conclusion & Implications

This study is the first of its kind to make an international comparison of sources of financial support for end of life caregivers. We have identified several areas of concern most notably a lack of clarity around process, limited opportunities for working carers to be supported while remaining in work, and considerable inequity in provision. Numerous barriers exist to the receipt of financial support and support may be insufficient to prevent significant financial hardship. Nonetheless, there is significant potential for policymakers to learn from other countries experiences, particularly with regard to the scope of financial support and the way support is operationalised for different groups of carers and patients.

[Table 6 about here]

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Declaration of conflicts of interest The Authors declare that there is no conflict of interest.

Data management and sharing. Data can be obtained from the authors on request. The survey used to collect data can also be obtained from the authors on request.

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Inclusion criteria.			
•	Written in English language (or translation available)		
•	Relates to one of the following countries Australia, Canada, Ireland, New Zealand, United Kingdom (UK), United States of America (USA).		
•	Relates to a source of financial support including (but not limited to): welfare and benefits, legislation, grants, tax credits, subsidy/co-payment schemes, provision of free services etc.		
•	Relates to ‘family caregivers’ as defined above		
•	Relates to a source of financial support that is available to carers of patients approaching the end of life (N.B. the financial support does not have to be <i>exclusively</i> aimed at end of life carers, and may include sources of support available to <i>any</i> caregiver)		
•	Relates to adult carers of adult patients (>18 years)		

Table 1: Inclusion criteria for grey literature searches and academic database searches

Country	Financial support for time commitment of caring		Bereavement/ funeral payments	Conditions
	Direct support (paid to carer)	Indirect support (paid to patient)		
Australia	Yes ^a	Yes	Yes ^b	a. Income and asset tested b. Type and amount depends on circumstances
Canada	Yes ^a	Yes	Yes ^b	a. Only country to provide a carer payment specific to end of life - the Compassionate Care Benefit b. Means tested
Ireland	Yes ^a	Yes ^a	Yes ^b	a. Means tested b. Various schemes, different eligibility apply
New Zealand	Yes ^a	Yes ^b	Yes ^b	a. For carers of those who would otherwise need hospital care, spouses are excluded. b. Means tested
UK	Yes ^a	Yes ^b	Yes ^c	a. Means tested b. Financial support for patients (but not carers) can be fast-tracked for people with terminal illness; but definition of ‘terminal’ differs across UK b. Not means tested
USA	Some ^a	Yes ^b	Some ^c	a. A small number of states offer paid leave for employees to provide care under Family & Medical Leave Act. b. Dependent on working history. Can be fast-tracked if patient has ‘Compassionate Allowance Condition’ inc. cancer but excluding other life limiting conditions. c. Most states provide nothing, minority (e.g. New York) offer paid bereavement leave from employment.

Table 2: Financial support for the time commitment of caring, by country

	Protection of employment rights for carers	Pension/tax credits for carer	Conditions
Australia	No ^a	Yes	a. Employers may sign up to a ‘Work and Care Charter’ to protect carer rights, but up to discretion of individual employers.
Canada	Yes ^a	Yes ^a	a. All provinces now allow job-protected leave from 8 to 28 weeks with varying definitions of a ‘family member’ b. Tax credits available for carers
Ireland	Yes ^a	Yes	a. Employees who have at least one years service may take job protected leave of up to two years
New Zealand	No ^a	No ^b	a. Employees have the right to request flexible hours, and employers must consider request

			b. May be eligible for reduced rates/tax credits if they meet other criteria.
UK	Yes ^a	Yes ^b	a. Employees have the right to take a 'reasonable' amount of unpaid time off work to deal with an emergency involving a dependant. b. Pension credits available, conditions apply
USA	Yes ^a	No	a. Family and Medical Leave Act provides 12 weeks of unpaid and job protected leave for caregiving for those with >12 months employment.

Table 3: Employment related rights and support, by country

	Home adaptation, equipment	Travel or transport costs	Energy costs & utilities	Concessions for carers	Charitable grants	Accommodation & food	Conditions
Australia	Yes ^a	Yes ^b	Yes	Yes ^c	Yes	Yes ^b	a. Means tested b. Subsidy scheme for patients living > 100km from healthcare provider. c. 'Companion card' in most territories allows carers to access venues free
Canada	Yes ^a	Yes ^b	No	Yes ^c	Yes	Yes ^b	a. Means tested, varies by province b. Only covers travel outside of home community to access healthcare. May include cost of an 'escort'. c. Some national coverage.
Ireland	Yes ^a	Yes ^b	Yes ^c	Yes ^d	Yes	No	a. Various supports, all means tested. b. Limited, mostly local schemes c. As part of Household Benefits package d. Free travel companion card
New Zealand	Yes ^a	Yes ^b	No	Yes ^c	Yes	Yes ^b	a. Means tested, long waits. b. Only for those travelling long distances for treatment c. Some limited local schemes
UK	Yes ^a	Yes ^b	No	No ^c	Yes ^d	No	a. Amount varies across UK b. Limited, considerable variation across UK c. No national scheme, some local concessions d. Dominated by cancer charities
USA	Yes ^a	Yes ^a	No	No ^b	Yes	No	a. Federal benefit but only for >60's. b. No federal program but may be flexibility with individual operators

Table 4: Support for out of pockets costs for carers/patients

	Reduced cost or free medications for patient	Reduced costs of healthcare for patient	Respite for carer	Conditions
Australia	Yes ^a	Yes ^b	Yes ^c	a. Various schemes for patients, also concessions for carers b. Schemes for those with high costs and those with palliative care needs. c. Availability poor
Canada	Yes ^a	n/a ^b	Yes ^c	a. Covers prescription drugs for palliative care patients. b. Healthcare free at point of access c. Varies by province, disparities of access exist, based on income, geography or health condition of the patient.
Ireland	Yes ^a	Yes ^a	Yes ^b	a. Holders of a Medical Card have free healthcare/prescriptions but means tested. High users also have drug costs capped. b. Termed 'carer's support grant' formerly called respite care grant.
New Zealand	Yes ^a	Yes ^b	Yes ^c	a. Once you've paid for 20 prescriptions each year subsequent prescriptions are free.

				<p>b. Schemes to reduce healthcare costs for those receiving certain benefits or with high usage.</p> <p>c. Respite scheme for unpaid, full time carers</p>
UK	Yes ^a	n/a ^b	Yes ^c	<p>a. Cancer patients automatically eligible for free prescriptions, other conditions must meet various criteria</p> <p>b. Healthcare free at point of access</p> <p>c. May be offered by local council, limited coverage</p>
USA	Yes ^a	Yes ^b	Yes ^c	<p>a. Those receiving Medicare/Medicaid Hospice Benefit get free drugs. Prescription drugs not usually covered by Medicaid, but can apply for free access to Medicare Prescription Plan (which pays up to an annual threshold).</p> <p>b. Free services for those receiving Medicare/Medicaid Hospice Benefit, which requires giving up all curative care</p> <p>c. For those receiving Medicare/Medicaid Hospice Benefit</p>

Table 5: Support for costs related to healthcare

Australia				
Carers strategy/policy:		<ul style="list-style-type: none"> • Carer Recognition Act (2010) 		
Palliative Care strategy/policy:		<ul style="list-style-type: none"> • National Palliative Care Strategy (2010) 		
Type of support		Name	Description	Conditions
Government support	Direct support (paid to carer)	Carer Payment	Income support if you are unable to work because of the demands of a caring role.	Available to those caring for someone with a terminal illness. Means tested.
		Carer Allowance	Smaller income supplement for people who provide daily care for someone who is frail, aged, or who has a severe disability.	Not means tested.
	Indirect support (paid to patient)	Disability Support Pension	Financial help if you have a permanent condition that stops you from working.	Means tested. Only for those under pensionable age.
	Bereavement/funeral payments	Bereavement Payment & Allowance	A lump sum or short term payment when the person you were caring for has died.	Type and amount of payment depends on individual circumstances. Those receiving Carer Payment automatically qualify.
Employment related rights and support	Protection of employment rights	Work and Care Charter	Promotes flexible working hours, flexible leave for carers with no fear of reprisal.	Voluntary charter with no obligation for employers to sign up.
		Right to request flexible working	All employees have a right to request flexible working to provide care.	Employers can refuse request.
	Tax or pension credits	Tax offsets	Carers of those with a disability may be eligible for reduced tax on any taxable income.	Dependent on benefits received by cared for person.
		Pension Supplement – (includes Goods and Service Tax (GST) Supplement)	A combined payment including GST Supplement.	For those receiving an existing benefit including Carer's Payment.
Support for out of pocket costs	Home adaptation and equipment	National Disability Insurance Scheme	Supports people with a permanent disability and will pay for some aids and equipment	Currently being rolled out across Australia, not available everywhere. Scheme is for patient but can benefit carer.
		Home Care Package	A package of care to help a person to live independently, can include equipment and home modifications.	Disability or needs must not met through other services. Scheme is for patient but can benefit carer.
		Equipment Schemes e.g. Australian Capital Territory (ACT) Equipment Scheme	Funding to obtain and maintain a range of equipment in order to assist mobility, safety and general physical ability to live at home in the community.	For those ineligible to receive assistance from other schemes or private health funds. Scheme is for patient but can benefit carer. <i>N.B. Similar schemes available in other territories.</i>

	Travel costs, parking, fuel benefit	Transport support	Every territory has a scheme that provides financial help to people who need to travel long distances (>100km) for medical treatment. Many schemes also cover accommodation.	Considerable variation by territory. Usually subsidy schemes – and don't always cover full cost. Not clear if schemes cover carers costs as well
		Parking concessions e.g. Free parking New South Wales (NSW)	Free parking in NSW public hospitals for patients and carers.	For those requiring long term treatment or attending more than twice a week. <i>N.B. Similar schemes available in other territories.</i>
	Energy costs, utilities	Energy Supplement	An extra government payment to get help with energy costs.	For those receiving an existing benefit including Carer's Payment.
		Pension Supplement – (Utilities Allowance & Telephone Allowance)	A combined payment of Pharmaceutical Allowance, Utilities Allowance, GST Supplement and Telephone Allowance.	For those receiving an existing benefit including Carer's Payment.
	Concessions for carers travelling with a disabled person	Carer's Cards e.g. NSW Companion Card	Allows a person's carer free entry into some venues and events	For carer's of those with significant and permanent disability. <i>N.B. Most territories offer something similar</i>
	Charitable grants	Hardship grants e.g. Redkite Financial Assistance Programme	Grants to help cover the costs of many essential items, utility bills, care costs, mortgage and rent, food vouchers.	For people with cancer. Grants aimed at patient but can benefit carer. <i>N.B Many other examples of charitable grants exist, not always cancer specific.</i>
	Accommodation and food	Transport support	See above under 'Travel Costs'	
Support for costs related to healthcare	Reduced cost or free medications for patient	Pharmaceutical Benefits Scheme (PBS)	Concessions for medications on the 'PBS list', full price must be paid for items not on the list.	Those in receipt of Carers Payment also entitled to PBS. Doesn't cover full cost of medication, only gives a concession. Not all medications covered.
		Pharmaceutical Benefits Scheme Safety Net	Provides listed medicines cheaper/free if you spend over a threshold amount each year.	Threshold level decided each year. Anyone can apply for the safety net.
		Pension Supplement	Includes a pharmaceutical allowance component (see above under energy costs)	Aimed at patient but those receiving Carer's Payment also qualify.
	Reduced costs of healthcare for patient	Medicare Safety Net	Provides a rebate for out of hospital costs for those who have significant healthcare costs	Various threshold levels. Rebates vary from 80% to 100% depending on circumstances.
		Medicare Hospice Benefit	Covers most of the costs related to hospice care (exc some drugs)	Must be deemed terminally ill (< 6months to live) to qualify. Must stop all curative care.

	Respite for carer	Carer Respite	National Disability Service can provide planned respite.	Availability is poor.
		Medicare Hospice Benefit	Provides respite of up to 5 days for carers of those in receipt of Hospice Benefit	Can be used more than once, but only on an 'occasional' basis. Covers up to 95% of cost.

Canada				
Carers strategy/policy:		<ul style="list-style-type: none"> • A Canadian Carer Strategy (2013) 		
Palliative Care strategy/policy:		<ul style="list-style-type: none"> • No current strategy, but a 2017 bill compels government to develop a Pan-Canadian palliative care framework within 5 years. 		
Type of support	Name	Description	Conditions	
Government support	Direct support (paid to carer)	Compassionate Care Benefit (CCB)	Benefit for people who have to be away from work temporarily to provide care to a family member/friend expected to die within six months. Max of 26 weeks, basic rate is 55% of average earnings, up to a yearly maximum.	Only for carers in paid employment. Regular weekly earnings from work must have decreased by > 40%; person must have sufficient insured working history. Can be shared between different carers. Payment is taxable income.
		Employment Insurance (EI) Family Caregiver Benefit for Adults	Payments for up to 15 weeks to care for a critically ill family member/friend. Amount varies depending on wages. Can be taken consecutively with CCB.	As above.
		Provincial caregiver benefit e.g. Nova Scotia Family Caregiver Benefit	Benefit for those providing > 20hrs care a week, and on low incomes.	Means tested and only for those on low income. <i>N.B. Other provinces may provide similar, but no federal caregiver benefit</i>
	Indirect support (paid to patient)	Canada Pension Plan (CPP)	Provides disability benefits to people who are disabled (inc terminal illness) and unable to work. Fixed basic monthly amount, plus an amount based on previous CPP contributions.	Dependent on patient having enough contributions to CPP over working career.
	Bereavement/funeral payments	Death Benefit	One off lump sum payment following death.	Deceased must have made sufficient tax contributions. Amount received depends on contributions.
		Allowance for the survivor	One off lump sum payment following death.	Only for those aged 60-64 and on low income. Amount depends on earnings
Employment related	Protection of employment rights	Compassionate Care Leave	All employees can take unpaid, job-protected leave of 8 - 28 weeks in a 52-week period to provide care for family member/friend at risk of death within 6 months.	Available in all provinces but significant variation in amount of time allowed off and definition of family caregiver.

	Tax or pension credits	Canada Caregiver Credit/Disability Tax Credit	Non-refundable tax credit for those caring for someone with a disability.	Amount depends on relationship to patient, carers circumstances, the cared for person's net income, and other credits being claimed. <i>N.B. some (few) provinces also provide refundable tax credits.</i>
Support for out of pocket costs	Home adaptation and equipment	Extended Health Benefits	Provincial benefit to pay for medically necessary supplies and equipment.	Only for minor supplies/equipment, not major adaptations. Must have one of a list of conditions. Each province operates own scheme. Aimed at patients but carer may benefit.
		Canadian Red Cross Health Equipment Loan Program	Loans health equipment to those with disabilities.	Only available in some provinces. Aimed at patients but carer may benefit.
		Home & Vehicle Modifications e.g. Ontario Home & Vehicle Modification Program	Provides funding for basic home and/or vehicle modifications for those with a disability.	Means tested. Only for those living in Ontario. Aimed at patients but carer may benefit. <i>N.B. Similar programs exist in some other provinces, but not in all.</i>
	Travel costs, parking, fuel benefit	Extended Health Benefits	Provincial benefit that can reimburse transportation expenses incurred when travelling to access medical treatment not available in home community.	Must have one of a list of conditions. Only covers travel costs for outside home community. May cover cost of an 'escort' but not clear if this includes a family carer. Each Canadian province operates its own scheme, but broadly similar.
	Energy costs/utilities	-	Nothing specific for carers but may qualify for generic 'Electricity Support Programme' or energy grants if on low income	
	Concessions for carers travelling with a disabled person	Free entry to venues e.g. Access2	Allows carers free entry to various entertainment venues across Canada.	Cared for person applies for a card which can be used by carer.
	Charitable grants	Hardship grants e.g. Ceridian Cares	Grants for assistive devices, but also clothing and footwear, food and basic household needs, and personal development and recreation to those who qualify.	Means tested. Aimed at patients but carer may benefit. <i>N.B. Other examples of charitable grants exist, often disease specific.</i>
	Accommodation and food	Extended Health Benefits	Provincial benefit that can reimburse accommodation and meals when travelling to access medical treatment not available in home community.	Must have one of a list of conditions. Only covers accommodation costs for outside of home community. Each province operates own scheme. Not clear if cost of carer is covered.
Support for	Reduced cost or free medications for patient	Palliative Care Drug coverage	This program covers the costs of prescription drugs for palliative care patients who are in the late stages of terminal illnesses.	Must be deemed to be in the last 6 months of life. Slight variations in coverage by province.

	Reduced costs of healthcare for patient	N/A as healthcare free at point of access in Canada		
	Respite for carer	Various respite care options	All provinces have some provision for respite for family caregivers. There is usually an extended provision of respite during palliative care.	Policies vary across Canada. In some areas there is little or no cost to the user, in others there is a means assessment. Availability varies, remote and rural areas particularly problematic.

Ireland				
Carers strategy/policy:		<ul style="list-style-type: none"> The National Carers Strategy (2012) 		
Palliative Care strategy/policy:		<ul style="list-style-type: none"> Palliative Care Services Three Year Development Framework 2017 to 2019 (2017). 		
Type of support		Name	Description	Conditions
Government support	Direct support (paid to carer)	Carer's Allowance	For those on low incomes caring for someone who needs support because of age/disability/illness.	Means tested and dependent on receipt of other benefits. Carer's must be providing full time care and not in employment
		Carer's Benefit	A payment for up to 24 months to people who give up employment or work less than 15hr/week to provide full time care.	Dependent on carers working history/previous tax contributions. Must have given up work (or work <15hrs/week) to provide full time care.
		Carer's Support Grant (formerly Respite Grant)	Annual payment (non means tested). It can be spent entirely at the discretion of the carer.	Carer must not be working for > 15 hours/wk or be receiving Jobseeker's benefits. Must have provided full time care for at least six months.
	Indirect support (paid to patient)	Disability Allowance	Weekly means tested allowance for adults with a long term disability.	Means tested and person must be aged 16-66 years (those over 66 years transfer to pension).
		Invalidity Pension	Weekly payment to people who cannot work because of a long-term illness/disability and are covered by social insurance.	Subject to income tax. Must be aged 16-66 years and have made adequate social insurance contributions.
	Bereavement/funeral payments	Exceptional Needs Payment	Can help with the cost of a funeral if your income is low.	Means tested. Depends on circumstances and type of assistance applied for.
		Widowed or Surviving Civil Partner Grant	One off grant for those who have dependent children living with them at time of the death.	Only for those with dependent children living with them.
		Special Funeral Grant	One off payment to help with funeral costs	Only when death was the result of an accident at work, or death from an occupational disease

		Carer's Allowance/Carer's Benefit	Payment of these benefits continues for 12 weeks/6weeks after death respectively	See above under Direct support for details
		Disability Allowance/Invalidity Allowance	Payment of these benefits continues for 12 weeks/6weeks after death respectively	See above under Indirect Support for details
Employment related rights and support	Protection of employment rights	Carer's Leave Act	Entitles all employees to leave employment temporarily for 13 and 104 weeks to provide full-time care. Unpaid but job protected.	Must have worked for employer for 12 months. Unpaid.
	Tax or pension credits	Credited Social Insurance Contributions	Contributions to social insurance while caregiving.	Entitled if you receive Carer's Benefit, Carer's Allowance or are on Carer's Leave.
		Carers Pension Credit and Homemakers scheme	Contributions to pension while caregiving.	Entitled if you receive Carer's Benefit, Carer's Allowance
Support for out of pocket costs	Home adaptation and equipment	Exceptional Needs Payment	Can be used for bedding, visiting relatives in hospital, clothing in exceptional circumstances	Means tested, amount varies. Aimed at patients but carer may benefit.
		Disabled Person's Housing Grant Scheme	Assists those who require alterations to their homes as a result of disability. May cover up to 95% of the cost of works	Grant paid to patient, means tested. Aimed at patients but carer may benefit.
		Mobility Aids Grant	Grant to cover a basic suite of works to address problems associated with ageing.	Grant paid to patient but carer may benefit. Means tested.
	Travel costs, parking, fuel benefit	Parking concessions e.g. hospital free parking		Often for cancer patients
		Travel2Care	Limited assistance fund for cancer patients travelling to a designated cancer centre	Only for those with cancer who travel over 50km to a designated cancer centre.
	Energy costs/utilities	Household Benefits Package	A package of allowances, includes electricity/gas allowance and a free TV licence.	Available to those receiving Carer's Allowance or Disability Allowance, or those > 70 years
	Concessions for carers travelling with a disabled person	Free Travel Companion Card	People > 66, those with disabilities and their carers can travel for free on public transport (carer only free when accompanying patient)	Must be in receipt of Disability Allowance/Carer Allowance to be eligible. Or over 66 years.
	Charitable grants	Irish Hospice Foundation Hardship Fund Grant	For patients/families undergoing severe financial hardship as a result of life-limiting illness. Only once-off expenses are considered.	Accessed by palliative care professionals on behalf of patients and their families. Applications assessed on a case-by-case basis
	Accommodation and food	-		
Support for costs related	Reduced cost or free medications for patient	Ireland Medical Card	Provides free medications, prescription charges apply but up to a monthly maximum.	Available to those receiving welfare or on low wages.
		Drugs Payment Scheme	Pay over a maximum of in a calendar month for medications, and thereafter they are free	Open to any resident

	Reduced costs of healthcare for patient	Ireland Medical Card	Entitles holder to free GP visits and free medication. Prescription charges still apply. Also covers hospital services.	Available to those receiving welfare or on low wages.
		Long Term Illness Scheme	People suffering from certain conditions can get free medicines, and medical and surgical appliances for the treatment of that condition.	Only 16 conditions listed (includes various neurological conditions but excludes cancer/organ failure/dementia)
		Carers GP visit card	Free GP visits for those receiving Carer's Benefit or Carer's Allowance.	Must be receiving Carer's Benefit or Allowance.
	Respite for carer	Carer's Support Grant (formerly Respite Grant)	Payment to be used at discretion of carer, often used for respite and was formerly known as respite payment.	See above under carer benefit for full details.

New Zealand				
Carers strategy/policy:		<ul style="list-style-type: none"> • Carers Strategy Action Plan (2014) 		
Palliative Care strategy/policy:		<ul style="list-style-type: none"> • New Zealand Palliative Care Strategy (2001) 		
Type of support		Name	Description	Conditions
Government support	Direct support (paid to carer)	Supported Living Payment	Payment for those caring for someone at home who would otherwise need hospital treatment. Amount depends on circumstances.	Carer must NOT be spouse or partner, and must be caring for someone at home full time who would otherwise need hospital care. Means tested.
	Indirect support (paid to patient)	Supported Living Payment	Benefit for people who have a permanent and severe disability that stops them working. Includes where an illness is terminal and the person isn't expected to live more than 2 years.	Means tested. Cannot be paid to patient AND carer at the same time.
		Disability Allowance	Payment for people who have regular ongoing costs because of a disability. Amount varies according to persons age and circumstances.	Means tested. Relatively small weekly payment. Receipts need to be kept

		Funded Family Care	Funding for people with high or very high needs to employ a family member to care for them.	Carer must be a parent/family member who lives with the patient and is NOT a spouse or partner.
	Bereavement/funeral payments	Funeral Grant	To help with the costs of a funeral.	Means tested.
Employment related rights and	Protection of employment rights	Right to request flexible working	All employees have a right to request flexible working to provide care. Employers have a “duty to consider”	Employers can refuse request.
	Tax or pension credits	-	Nothing specific for carers, although they may be eligible for reduced rates/tax credits if they meet other circumstances	
Support for out of pocket costs	Home adaptation and equipment	Equipment and modifications for disabled people	Government support for equipment and modifications to home or vehicle to help with everyday activities, for those with a disability. Government can also loan some equipment.	Dependent on an assessment. May pay all or part of the costs of modifications. Can only apply for modifications once. Can take a long time. Scheme is for patient but can benefit carer.
	Travel costs, parking, fuel benefit	National Travel Assistance	Government reimbursement for travel by private car, public transport, air travel, taxi and accommodation for those who travel long distances to access healthcare or are high frequency users.	Eligibility depends on distance from healthcare provider (> 350km one way or >80km if holder of community services card) or frequency of visits. Only reimburses patient, carer must pay own costs. Maximum amounts are set and can be limiting if costs go beyond this. Some variation in criteria across the country.
		Total Mobility Scheme	Subsidised taxi service for those with a disability, giving a 50% discount on normal taxi fares.	Aimed at patients, but carers may benefit.
	Energy costs, utilities	-	Nothing specific for carers but may qualify for Winter Energy Payment if of pensionable age or receiving another benefit. Carers may also qualify for generic grants/loans if on v.low income but may be ineligible if receiving other benefits	
	Concessions for carers travelling with a disabled person	Free entry e.g. free entry to Te Matatini festival	Carers offered free entry to this festival when accompanying a cared for person.	Offered by many venues but on an ad hoc basis. No national scheme for carer concessions.
	Charitable grants	Hardship grants e.g. Sweet Louise	Provides an annual allocation of vouchers for services such as house cleaning, lawn mowing, massage, meal deliveries and much more.	Only for those with advanced breast cancer. Grants aimed at patients but can benefit carer. <i>N.B. Other examples of charitable grants exist</i>
	Accommodation and food	National Travel Assistance	Reimburses accommodation costs of up to a threshold amount for those who travel long	Eligibility depends on distance from healthcare provider (> 350km one way or >80km if holder

			distances to access healthcare or are high frequency users.	of community services card) or frequency of visits. Only reimburses patient, carer must pay own costs
Support for costs related to healthcare	Reduced cost or free medications for patient	Community Services Card	Can reduce costs of prescriptions	Benefit for patient, not carer. Must be low/middle income to be eligible.
		Prescription Subsidy Card	Reduces prescription costs for those who are prescribed a lot of medicines.	Benefit for patient, but carer may also be eligible. Eligible once you (& any eligible family members) have paid for 20 prescriptions each year, from then on prescriptions are free.
	Reduced costs of healthcare for patient	Community Services Card	Can reduce costs of doctors fees and home help.	Benefit for patient, not carer. Must be low/middle income to be eligible.
		High Use Health Card	Entitles frequent health service users to reduced costs for some doctor visits and some prescriptions. The card is valid for 1 year.	A patient must have received at least 12 health practitioner consultations within the last 12 months for ongoing medical condition(s).
	Respite for carer	Carer Support Subsidy	Government subsidy which offers full time carers respite by contributing to cost of an alternative carer, for a specific number of days per year depending on needs assessment	Only for unpaid, full time carers. Number of days respite is based on a needs assessment. Payments may be taxed.
		Individualised funding (IF)	Government payment to a person with a disability that can be used to pay for respite for their carer	IF payments must be managed by an IF Host Organisation.

UK			
Carers strategy/policy:		<ul style="list-style-type: none"> National Carers Strategy for England (2003); The Carers Strategy for Scotland 2010-2015 (2010); The Carers Strategy for Wales (2013); The Carers Strategy for Northern Ireland (2006) 	
Palliative Care strategy/policy:		<ul style="list-style-type: none"> End of Life Care Strategy for England (2008) Living and Dying Well: A National Action Plan for Palliative and End of Life Care in Scotland (2008) 	
Type of support	Name	Description	Conditions
Government support	Direct support (paid to carer)	Carer's Allowance	Payment for those providing at least 35 hours of care a week. Also protects carers pension
		Universal Credit	If unable to work due to health problems or caring responsibilities then a person may be entitled to universal credit.
			Patient must be in receipt of certain benefits; carer must not earn over certain threshold.
			Must be under state pension age, must meet certain income related or contributory criteria, must attend job centre with cared for person.

	Indirect support (paid to patient)	Personal Independence Payment	Help with some of the extra costs caused by long term ill-health or disability.	Those with a terminal illness can be fast-tracked and will receive highest rate. Definition of 'terminal illness' varies across UK.
		Attendance allowance	Help with costs for those who need someone to help look after them. Can be used to pay a family member/friend as a carer.	Those with a terminal illness can be fast-tracked and will receive highest rate. Definition of 'terminal illness' varies across UK.
	Bereavement/funeral payments	Bereavement Support Payment	One off lump sum followed by 18 monthly payments of for spouses/civil partners.	Not means tested. Amount depends on having any dependents at time of death. Only for spouses/civil partners.
		Funeral Expenses Payment	Payment to help with the cost of a funeral, for those on a low income.	Means tested and deductible from any money received from deceased's estate.
		Carer's Allowance	Usually continues to be paid for eight weeks after the death of the cared for person	See above – under Carer's Allowance
Employment related rights and support	Protection of employment rights	Time off for Dependents	Statutory right for all employees to have the right to 'reasonable' job protected time off for dependants, to deal with unforeseen matters and emergencies.	No set limit to how much time can be taken off, definition of 'reasonable' is up to discretion of employer. No automatic right to be paid.
		'Dying to Work Charter'	Voluntary charter which employers can sign up to, which protects the employment rights of those with a terminal illness	Applies to patient rather than carer. Voluntary charter so no obligation for employers to sign up.
	Tax or pension credits	Council tax discount	Carer can be treated as not living in a property to reduce council tax.	Must provide care for min 35 hours/week and must not be the spouse or partner of patient.
		Carer's Credit	Protects pension rights for people who are caring for someone but are not paying National Insurance (NI) contributions	For those providing care for min of 20 hours/week but not claiming carers allowance.
Support for out of pocket costs	Home adaptation and equipment	Disabled Facilities Grant	Payments to cover significant home modifications e.g. adapted heating/ lighting, widening doorways, stairlifts. Minor adaptations in the home are provided free.	Payment for patient that benefits carer. Means tested. Have to own property or intend to live in house for 5 years if renting. Maximum amount varies across countries of the UK.
	Travel costs, parking, fuel benefit	Blue Badge Scheme	Allows holder to park in disabled parking bays, and to park for free in council owned pay and display care parks.	Free parking only in council owned car parks. Scheme is for patient but can benefit carer when travelling together. Small cost to buy the badge.
		Disabled Bus Pass (England)/National Entitlement Card (Scotland)	In some circumstances, carers can travel for free if the cared for person holds one of these.	Considerable variation across the UK.

		Disabled Person's Railcard	Offers discounts on rail travel for carers	Gives a discount for carers but some payment still required.
		Local parking concessions e.g. free parking at Sheffield Teaching Hospitals NHS Trust	Parking pass provided following diagnosis of a terminal illness, allows free parking in hospital car parks in this NHS Trust	Only applies to this NHS Trust. Scheme is for patient but can benefit carer when travelling together. <i>N.B. Numerous other examples across the UK, operated locally by NHS Trusts. May also include refunds on travel costs.</i>
	Energy costs, utilities	-	Nothing specific for carers but may qualify for generic support e.g. Winter Fuel Payment (>65yrs), Warm Home discount scheme if on low income, or hardship grants from energy companies.	
	Concessions for carers when travelling with patient	Free/discounted entry for carers	Many venues/events offer free or discounted entry to carers when accompanying a person with a disability e.g. National Trust.	No national scheme for carer concessions. Requirements vary depending on venue.
	Charitable grants	Hardship grants e.g. Macmillan Cancer Care grants	Small one off payments to help with the extra costs caused by cancer.	Only for people with cancer, means tested. Grants are for patient but can be benefit carer. <i>N.B Various other examples from other charities (serving other conditions) across the UK.</i>
	Accommodation and food	-		
Support for costs related to healthcare	Reduced cost or free medications for patient	Free prescriptions	Free prescriptions for those with a Medical Exemption (MedEx) certificate.	Only for people with cancer or those with 'continuing physical disability that means the person can't go out without the help of another'
	Reduced costs of healthcare for patient	N/A as healthcare free at point of access in UK		
	Respite for carer	Carer's breaks and respite care	In certain situations, respite care may be provided by local council after an assessment	Dependent on a carer/patient assessment by local council

USA			
Carers strategy/policy:	<ul style="list-style-type: none"> None (however the recent Recognize, Assist, Include, Support and Engage (RAISE) Family Caregivers Act commits to the establishment and maintenance of a Family Caregiving Strategy End) 		
Palliative Care strategy/policy:	<ul style="list-style-type: none"> None 		
Type of support	Name	Description	Conditions

Government support	Direct support (paid to carer)	No federal program but some states provide 'Paid Family and Medical Leave'	A small number of states provide paid leave from employment to provide care. Duration varies but typically between 4-12 weeks.	Only for those in employment. Significant variation by state. Cared for person must be spouse, child or parent. May not cover full salary.
		Limited additional state specific support available e.g. Kapuna Caregivers Act - Hawaii	Provides a daily stipend for people who work at least 30 hours/week while also caring for an elderly family member.	Only in Hawaii. Must work for at least 30 hrs/week in addition to caring role. Must be caring for someone over 60 years.
	Indirect support (paid to patient)	Federal Social Security Disability Insurance	Pays benefits to patient and certain family members of those who are "insured", meaning those who have paid sufficient Social Security taxes.	Must have made enough social security contributions over working career. Can be fast-tracked if patient has a 'Compassionate Allowance Condition' which include cancer.
		Federal Supplemental Security Income	Pays benefits to disabled people based on financial need.	Means tested.
		Some other state specific support available e.g. In Home Supportive Services (IHSS) - California	Assists older persons and adults with disabilities to remain in their own homes by helping to pay for: cleaning, meal prep, laundry, shopping, personal care services. Allows cared for person to choose who to hire, including relatives or friends.	Must be aged over 65 years OR meet disability criteria and be on low income.
	Bereavement/funeral payments	No federal program but some states provide support e.g. Paid Bereavement Leave – New York	Employees given three months paid leave (at ~50% of earnings) after the death of a close family member.	Only for those in employment. Cared for person must be spouse, child or parent. Significant variation by state.
Employment related rights and support	Protection of employment rights	Federal Family and Medical Leave Act	Provides up to 12 weeks of unpaid leave and job protection for those caring for a spouse, child, or parent with a serious health condition.	Cared for person must be spouse, child or parent. Carer must have > 12 months of employment.
	Tax or pension credits	Federal Family and Medical Leave Act	Social security/insurance contributions will be covered whilst a carer is absent from work.	As above. Only applies to carers in employment.
Support for out of	Home adaptation and equipment	National Family and Caregiver Support Program	Federal program providing various supports including home modifications.	Cared for person must be > 60 years. Benefit is for patient, but may benefit carer.
	Travel costs, parking, fuel benefit	National Family and Caregiver Support Program	Federal program providing various supports including transport	Cared for person must be > 60 years. Benefit is for patient, but may benefit carer.

	Energy costs/utilities	-	Nothing specific for carers but they may be eligible for generic 'Low Income Home Energy Assistance Program' if on v. low income.	
	Concessions for carers travelling with a disabled person	-	No federal/state wide programs – although may be some flexibility with individual travel operators	
	Charitable grants	Hardship grants e.g. Cancer Care	Grant to help with transportation, home care, childcare and some medical costs. Doesn't cover basic living costs – rent, food etc.	Means tested. Charitable grants are often for people with specific conditions e.g. cancer. Religious groups often offer similar support. Grants usually for patient, but may benefit carer.
	Accommodation and food	-		
Support for costs related to healthcare	Reduced cost or free medications for patient	Medicare/Medicaid Hospice Benefit	Federal benefit providing free healthcare for Medicare/Medicaid beneficiaries with terminal illness. Covers costs of all prescription drugs and includes respite for carer. No restrictions on length of time a patient can receive the benefit for.	Requires patient to give up all curative care. Two physicians must certify they have terminal illness and regular re-assessments are required. Usual Medicaid/Medicare conditions apply e.g. age > 65 years or certain disabilities to be eligible for Medicare, and low income to be eligible for Medicaid.
	Reduced costs of healthcare for patient	Medicare/Medicaid Hospice Benefit	As above	As above
	Respite for carer	Medicare/Medicaid Hospice Benefit	As above	As above
		National Family and Caregiver Support Program	Federal program providing various supports including carer respite.	Cared for person must be > 60 years

Table 6: Summary profiles of financial support for family caregivers of those at the end of life across Australia, Canada, Ireland, New Zealand, UK and the USA.