# Prassi e legislazione sul fine vita in vari Paesi del mondo

Questo capitolo copre la descrizione di *Prassi e legislazione sul fine vita in vari Paesi del mondo.*
I testi sono tratti ***per I Paesi contrasegnati con **** dalla appendice dell'ultima edizione in spagnolo del mio libro *L'amore, sempre:* Attilio Stajano **Amar hasta el final** *Los cuidados palliativos frente al desafío de la eutanasia,* Prefacio de Marie de Hennezel *Tradujo José Ángel Velasco Garcia del original italiano* Ediciones Sígueme, 222 páginas, 2020, ISBN 978-84-301-2072-7 .
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Italia, Francia e Belgio non sono qui presenti perché trattati nel corpo del libro a stampa.

I Paesi qui trattati sono:
- **Austria***
- **Germania***
- **Regno Unito***
- **Spagna***
- **Svizzera***
- **United States of America#**
- **Canada#**
- **Ireland#**
- **Australia#**
- **New Zealand#**
- **South Africa#**

**Note a Prassi e legislazione sul fine vita in Paesi contrassegnati con #**

# Austria

In Austria (8 milioni di abitanti) ci sono 20 equipe di cure palliative in ospedale e 58 equipe che offrono servizi domiciliari, oltre a 68 posti letto in otto hospice, alcuni dei quali sono integrati in case di riposo (0,7 letti per 100 000 residenti), a seguito del riconoscimento da parte del servizio sanitario nazionale della necessità di cure palliative nelle case di cura; un hospice è dedicato a cure pediatriche[i].

Le cure palliative sono per il 50 per cento a carico del servizio sanitario nazionale e ne costituiscono una componente integrata nella sua struttura globale. Il 30 per cento dei fondi proviene da organizzazioni non lucrative di utilità sociale (ONLUS) e il 20 per cento da organizzazioni private[ii].

La legislazione nazionale austriaca copre le disposizioni anticipate di trattamento, e accorda ferie retribuite per i familiari che assistono un malato in fin di vita[iii].

In Austria l'eutanasia è vietata dalla legge penale. Tuttavia, l'opinione pubblica in Austria è, secondo un sondaggio del 2009, per il 71 per cento a favore dell'eutanasia[iv].

Il divieto del codice penale relativo alla eutanasia è esteso all'assistenza al suicidio. La sospensione di misure artificiali di sostegno alla vita è consentita e può essere legalmente richiesta dal paziente, anche attraverso le disposizioni anticipate di trattamento[v].

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# Germania

Una legge federale del 2009 sancisce in Germania (82 milioni di abitanti) il diritto universale alle cure palliative e rende obbligatoria la formazione in cure palliative nei piani di studio per la laurea in medicina.

In Germania, oltre il 40 per cento delle morti ha luogo in ospedale, meno del 30 per cento a casa e oltre il 20 per cento in case di cura; negli hospice e nei reparti di cure palliative termina la vita solo meno del 4 per cento dei cittadini tedeschi. Contrariamente a quanto avviene altrove, in Germania i reparti di cure palliative negli ospedali non sono un servizio per l'accompagnamento alla fine della vita, ma piuttosto un reparto finalizzato al superamento delle fasi critiche per malati inguaribili, in vista di un loro ritorno a casa o nella casa di cura medicalizzata da dove provengono; il loro soggiorno è in media di due settimane e il numero di dimissioni supera il 50 per cento.

In Germania ci sono 241 equipe di cure palliative in ospedale e 180 equipe che offrono servizi domiciliari, oltre a 1729 posti letto in 179 hospice (2 letti per 100 000 residenti). Ci sono 97 equipe di cure palliative pediatriche e 26 di cure palliative pediatriche domiciliari[vi].

Nelle cure palliative in Germania un ruolo centrale è quello del medico di base, accompagnato e assistito dalle equipe specializzate in cure palliative domiciliari (SAPV)[vii], istituite nel 2007. Le SAPV entrano gradualmente in funzione in tutto il paese. Ciascuna serve un territorio che comprende 250 000 residenti. Una equipe di Monaco, istituita nel 2009 ha consentito all'82 per cento degli assistiti di morire a casa.

Le fonti di finanziamento per le cure palliative sono miste in Germania: il 5 per cento dei finanziamenti proviene da fondi pubblici, il 55 per cento da organizzazioni non lucrative di utilità sociale (ONLUS) e il 40 per cento da organizzazioni private.[viii]

Il suicidio non è un reato secondo la legge tedesca e l'aiuto al suicidio rimane impunito. Tuttavia, la giurisprudenza esamina se vengano commessi altri reati, per esempio omicidio colposo o omissione di soccorso. L'attenzione si è concentrata sulla questione se gli aiuti al suicidio attualmente consentiti, ad esempio fornendo medicinali, debbano essere vietati in futuro. Dopo un dibattito durato 18 mesi, nel novembre 2015 il Parlamento federale ha approvato un disegno di legge che criminalizza l'assistenza al suicidio a scopo di lucro. Un passo verso la legalizzazione della assistenza al suicidio è stato fatto in Germania nel 2020[ix], con una sentenza della Corte Costituzionale tedesca di Karlsruhe, che ha dichiarato l'incostituzionalità dell'articolo 217 del codice penale tedesco, che puniva fino a tre anni di reclusione il favoreggiamento del suicido a fini di lucro. La sentenza trova la sua giustificazione nel principio di dignità umana (Menschenwürde), menzionato nell'art. 1 della Costituzione. Ora spetterà al Parlamento provvedere a una nuova normativa che regoli la materia.

Nel 2014 è stato avviato un dibattito in Germania su una riformulazione legislativa sull'eutanasia. In Germania, qualsiasi forma di eutanasia, è illegale[x], mentre la sospensione di trattamenti medici che prolungano la vita è legale e generalmente accettata[xi]. Un problema nel dibattito è stata la questione della cosiddetta "organizzazione della morte" (organisierte Sterbehilfe). La morte per suicidio viene gestita da associazioni, ad esempio, "Sterbehilfe Deutschland e.V.", un'organizzazione che, in cambio di un pagamento annuale o vitalizio, offre consulenza e assistenza per l'attuazione del proprio progetto di morte. Questa offerta, non implica una partecipazione attiva né una violazione della legge penale esistente. Nella legislatura 2009-2013 si è stabilito il divieto di suicidio organizzato eseguito da enti a scopo di lucro. Con "a scopo di lucro" il legislatore intende in questo contesto un intervento retribuito di associazioni o individui.[xii]

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## Regno Unito

Le cure palliative sono nate nel Regno Unito (67 milioni di abitanti), che continua a essere il leader europeo nel loro sviluppo, in termini di quantità dei servizi offerti, alti standard e programmi di ricerca. Nel 2012, il Regno Unito ha emanato la Costituzione del Servizio Sanitario Nazionale (NHS)[xiii]. Tutti gli assistiti dal NHS hanno diritto all'accesso ai servizi sanitari, a cure di qualità, ai trattamenti e alle medicine, a consenso e riservatezza, alla scelta del trattamento, a assistenza sanitaria basata su necessità mediche e nessun altro fattore, alla scelta di un medico di base (GP), al diritto di cambiarlo senza difficoltà, al diritto al trattamento di emergenza, al diritto a un secondo parere in determinate circostanze, al diritto di dare consenso informato per il trattamento, al diritto di accesso alle cartelle cliniche e la garanzia della loro riservatezza, al diritto di rifiutarsi di partecipare alla ricerca medica e alla formazione medica, e al diritto di presentare reclamo e ricevere un risarcimento. I medici hanno il dovere di proteggere la vita e favorire la salute dei pazienti.

La giurisprudenza stabilisce una serie di principi rilevanti. Un certo numero di sentenze sulla sospensione, la rinuncia e il rifiuto del trattamento ha dimostrato che i tribunali non ritengono che la protezione della vita debba avere sempre la precedenza su altre considerazioni. I pazienti adulti capaci possono decidere di rifiutare il trattamento anche se il rifiuto può causare danni a se stessi o la morte. Riguardo ai pazienti che non hanno capacità di intendere, misure terapeutiche per il prolungamento artificiale della vita possono essere legittimamente negate o sospese, se tali misure non sono nel loro interesse. Non vi è alcun obbligo per i sanitari di fornire un trattamento che, a loro avviso, sia inefficace o fastidioso. Se i pazienti adulti hanno perso la capacità di intendere e di volere, un rifiuto di trattamento fatto quando erano capaci deve essere rispettato, a condizione che sia chiaramente applicabile alle circostanze presenti e non vi sia alcun motivo di credere che i pazienti abbiano cambiato idea.

Oggi il team di cure palliative del Servizio Sanitario Nazionale, entro 48 ore dalla presa in carica di un nuovo paziente, pone in essere un protocollo di cura, dopo aver valutati i desideri del paziente e i requisiti di cura.

I pazienti non hanno bisogno di allontanarsi dalle loro quattro mura (casa o casa di cura) per ricevere assistenza poiché la cura può anche essere fornita a domicilio, come servizio h24, sotto il controllo del medico di base (GP) o del servizio sanitario dell'NHS. In pratica, l'assistenza può essere fornita a casa, in una casa di cura, in ospedale, o in un hospice. Negli ospedali dove non c'è un reparto di cure palliative, ci sono team di cure palliative specializzate che lavorano a fianco dei medici ospedalieri, degli infermieri e degli altri operatori sanitari e sociali.

Gli aspetti legali delle cure di fine vita continuano ad evolvere nel Regno Unito come in molti altri paesi. Ad oggi, l'eutanasia è vietata in tutto il Regno Unito e qualsiasi atto in cui l'intenzione primaria del medico è quella di provocare la morte di un paziente è illegale[xiv]. Una proposta di legge volta a dare ai malati terminali il diritto di morire su loro richiesta[xv] non era passata prima delle elezioni generali del maggio 2015[xvi]. Questa proposta, discussa in Parlamento all'inizio del 2015, avrebbe fornito assistenza per porre fine alla propria vita su loro richiesta a pazienti in possesso delle facoltà mentali con un'aspettativa di vita inferiore a sei mesi. Un nuovo tentativo infruttuoso di approvare la proposta in materia si è verificato nella successiva legislatura. La Camera dei Comuni ha respinto dopo un animato dibattito il disegno di legge con 330 voti contrari e 118 favorevoli, chiudendo, presumibilmente, per molti anni a venire le discussioni sull'eutanasia nel Regno Unito[xvii].

I costi degli hospice sono coperti nel Regno Unito dal Dipartimento della Salute e dalle donazioni dalla comunità[xviii]. Un gran numero hospice in Inghilterra sono gestiti e finanziati in prevalenza dal quarto settore. In media, gli hospice per adulti in Inghilterra hanno ricevuto il 34 per cento dei loro costi di gestione dai fondi governativi. La percentuale effettiva dei finanziamenti statali per gli ospedali varia da zero al 62 per cento dei loro costi e il complemento viene da donazioni[xix].

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## Spagna

In Spagna (47 milioni di abitanti) ci sono circa 260 000 decessi all’anno, di cui 80 000 per cancro. Migliorare l'assistenza ai pazienti in fase avanzata e terminale è una delle sfide che il Ministero della salute ha affrontato a partire dalla metà degli anni '80, ispirato dalla esperienza di Dame Sanders in Inghilterra. Le misure usate includono il miglioramento dell'assistenza delle risorse sanitarie esistenti, lo sviluppo di nuove risorse orientate alle cure in fin di vita, la facilità d’accesso a antidolorifici oppiacei, e la formazione di professionisti e di volontari.

I primi servizi di cure palliative iniziarono nel 1984; la Sociedad Española de Cuidados Paliativos (SECPAL)[xx] fu fondata nel 1992, una rivista specializzata in cure palliative (Revista Medicina Paliativa) iniziò le pubblicazioni nel 1994 e nel 1995 fu tenuto a Barcellona il primo congresso di Cure Palliative, con oltre mille delegati.

Un Piano nazionale ben definito per le cure palliative fu formulato e messo in esecuzione nel 2001 dal Ministro della Salute, introducendo una Piano strategico di cure palliative nell’ambito del servizio sanitario nazionale per assicurare cure palliative di alta qualità per pazienti terminali oncologici e non oncologici in tutto il Paese, nel quadro dei servizi sanitari regionali.

Lo studio sulla qualità dei servizi sanitari in fin di vita in 80 Paesi del mondo pubblicato dall’Economist nel 2015[xxi] dedica alla Spagna un capitolo che illustra la pertinenza e l’efficacia delle misure adottate dal governo. Le politiche nazionali sono state fondamentali per estendere l'accesso alle cure palliative e hanno dato risultati tangibili: il lancio della strategia nazionale spagnola ha portato ad un aumento del 50% del numero delle equipe di cure palliative con strutture regionali unificate.
Le cure palliative sono finanziate dal bilancio sanitario nazionale come servizi forniti a livello di assistenza primaria. Al bilancio dello Stato si aggiungono finanziamenti da parte di organizzazioni private, organizzazioni non-governative e donatori individuali.

Come in molti altri Paesi si lamenta in Spagna una difficoltà all’accesso alle risorse in aree rurali e periferiche e una insufficiente copertura della domanda di cure pediatriche.

Numerosi sanitari sono ben formati alle cure palliative, la loro formazione è per altro assicurata solo in metà delle università e delle scuole superiori per infermieri. Le cure palliative sono insegnate in 22 istituti universitari di medicina (su 42) e in 69 scuole per infermieri (su 112). Mentre nelle università oltre la metà degli studenti di medicina intraprende programmi di cure palliative di base e a livello intermedio, manca ancora una procedura di accreditamento per le equipe specializzate in cure palliative.
Al Ministero della Salute è di ruolo personale politico e scientifico dedicato a tempo pieno alle cure palliative.

Un ruolo di primo piano è svolto dalla Sociedad Española de Cuidados Paliativos (SECPAL) che riunisce professionisti della salute che nelle loro attività quotidiane si prendono cura, e accompagnano i pazienti per i quali le terapie di guarigione non hanno più ragione d'essere: medici di famiglia, oncologi, anestesisti, infermieri, assistenti sociali, psicologi, religiosi, bioeticisti e volontari.
La Spagna ha un numero sufficiente di volontari per soddisfare le esigenze nel Paese e alcuni di questi ricevono una formazione e sono coinvolti in compiti di assistenza e accompagnamento e talvolta in programmi di raccolta di fondi.
Il pubblico ha una conoscenza e una consapevolezza limitate dei servizi di cure palliative. Insufficienti informazioni sulle cure palliative son disponibili sui portali governativi.

I centri di servizio per cure palliative sono 260, cinque per milione di abitanti, al livello di tre quarti della mediana europea. Sono suddivisi in 63 servizi in ospedale per pazienti residenti
Le unità mobili per pazienti in fin di vita nei vari reparti degli ospedali sono 88, una unità in hospice, 100 unità per l’assistenza domiciliare ed 8 unità di altra natura. Non ci sono reparti ospedalieri pediatrici di cure palliative, ma 8 unità di cure palliative pediatriche domiciliari e 2 unità pediatriche mobili in ospedale.
Il servizio di cure palliative a domicilio mira a controllare i sintomi e il dolore e a fornire supporto psicologico e sociale, fornendo anche continuità di assistenza. Le cure domiciliari sono di solito applicate a pazienti terminali che non sono affetti da patologie così gravi da richiedere l’ospedalizzazione. Quando è possibile i pazienti preferiscono restare nell’ambiente conosciuto e protetto della loro casa, ma talvolta questo non è possibile per la gravità delle patologie o per la indisponibilità dei familiari. L'accesso alle cure palliative a domicilio è assicurato dalla sicurezza sociale attraverso il sistema sanitario pubblico e viene richiesto dal medico di famiglia. La necessità di organizzare le

cure palliative domiciliari può essere molto urgente; esistono iniziative private che forniscono *caregiver* specializzati in cure palliative e assistenza domiciliare a tempo pieno o a ore[xxii].

I punti di forza della Spagna evidenziano il fatto che, anche nei paesi che hanno un ampio accesso a servizi di alta qualità, l'interazione tra politica, legislazione e formazione rimane fondamentale se l'offerta di servizi deve soddisfare la crescente domanda di assistenza[xxiii].

Uno studio[xxiv] ha rilevato che in Spagna un passaggio alle cure palliative, un aumento dei servizi di assistenza domiciliare e un uso inferiore dei pronto soccorso hanno generato un risparmio del 61% rispetto alle spese registrate nel contesto di cure ospedaliere convenzionali. Tuttavia, con l'invecchiamento della popolazione, nei prossimi anni saranno necessarie più cure per pazienti in fine di vita.

In Spagna esiste dal 2018 una legislazione specifica che regola il rifiuto, l'interruzione o la sospensione del trattamento per pazienti in fine di vita e in pazienti cronici in situazioni critiche, tenuti in vita da apparecchiature di supporto vitale[xxv]. Evitare il prolungamento irragionevole della vita e il ritiro o la sospensione di un supporto vitale considerato sproporzionato erano già da molti anni ritenuti una buona pratica clinica quando il paziente è d'accordo o si può assumere che lo sia. Alcune istituzioni indipendenti (che non rappresentano necessariamente la posizione dello Stato spagnolo), come l'Osservatorio di bioetica e diritto dell'Università di Barcellona, avevano elaborato già nel 2007 documenti sull'eutanasia e sulle direttive anticipate di trattamento[xxvi]. Allo stesso modo, l'uso di oppiacei per alleviare la sofferenza è considerato una buona pratica medica anche se questa pratica può avere l'effetto concomitante di abbreviare la vita. In realtà, la limitazione del trattamento è comunemente applicata nelle unità di cure intensive spagnole e questa pratica è accettata dalla stragrande maggioranza della comunità medica. I codici deontologici dei medici spagnoli si sono costantemente adattati ai cambiamenti nei quadri sociali e legali e si sono avvicinati sempre più a quelle posizioni che riconoscono la necessità di rispettare l'autonomia del paziente. I codici deontologici delle diverse società mediche in Spagna rifiutano esplicitamente trattamenti inutili, irragionevoli o sproporzionati, considerandoli un trattamento disumano o degradante. Per altro persistono problemi quotidiani nella comunicazione tra medici, pazienti e familiari, rendendo difficili le decisioni in merito all'assistenza di fine vita.

In Spagna, diverse istituzioni sono favorevoli a un dibattito aperto sulla depenalizzazione dell'eutanasia e alla creazione di una legislazione che regoli questo processo. Fino ad ora, tuttavia, il Parlamento non aveva preso in considerazione la possibilità di discutere sull'eutanasia come era già stato fatto in altri paesi europei. Il Comitato consultivo catalano di bioetica ha raccomandato la depenalizzazione dell'eutanasia e del suicidio assistito per le persone con condizioni terminali irreversibili che chiedono la morte assistita[xxvii].

La Costituzione spagnola[xxviii] nelle Sezioni 1 e 10, protegge e difende in modo inequivocabile la vita umana, ma non impone alcun obbligo di continuare a vivere contro la propria volontà personale in presenza di una sofferenza insopportabile. Viceversa, l'articolo 143 del Codice penale in vigore punisce, in diversa misura, l'eutanasia e il suicidio assistito. Alcuni giuristi ritengono che questo sia in contraddizione con la Costituzione, che prevale sul Codice penale. Tuttavia, per quanto mi consta, nessuno in Spagna è stato mai condannato in un tribunale per l'imputazione di eutanasia o di suicidio assistito.

La questione dell'eutanasia e del suicidio assistito era stata riportata alla ribalta nell'aprile 2019 dal caso, ampiamente coperto dai media, di Ángel Hernández, che aveva aiutato a morire la moglie, affetta da un grave caso di sclerosi multipla. Nel febbraio del 2020 una proposta di legge sulla eutanasia e il suicidio assistito[xxix] è stata discussa nel Parlamento spagnolo e approvata dalla camera bassa (Congreso de los Diputados), con 203 voti a favore e 140 contrari. Il partito conservatore popolare Vox di estrema destra è contrario, mentre un sondaggio del 2019 dell'agenzia spagnola Metroscopia misura che l'87% dei cittadini sostiene l'eutanasia per i pazienti incurabili e che circa i due terzi dei medici sono favorevoli al progetto di legge.

L'ex Primate di Spagna, Braulio Rodriguez Plaza, ha respinto le affermazioni dei promotori del progetto di legge secondo cui l'eutanasia incarnava un "nuovo diritto umano"  e avvertiva che la sua legalizzazione sarebbe stata un "peccato grave e dannoso; né l'eutanasia né il suicidio assistito renderanno la società migliore o più libera o saranno espressione di veri progressi”.

La proposta di legge introdurrebbe nel sistema legale l'eutanasia e il suicidio assistito per una persona che patisce per una sofferenza dovuta a una malattia incurabile o per una sofferenza che la persona ritiene inaccettabile e che non potrebbe essere in alcun modo mitigata. Con eutanasia la proposta intende l'azione che produce la morte di una persona direttamente e intenzionalmente attraverso una relazione causa-effetto unica e immediata, su richiesta informata, espressa e reiterata di detta persona. Con suicidio assistito la proposta intende la prescrizione e la fornitura al paziente da parte del professionista sanitario competente di una sostanza che possa essere auto-somministrata e causare la morte. Il personale sanitario ha il compito di presenza e supporto durante la auto-somministrazione, sia essa nel centro di cura o a casa. Così definiti, l'eutanasia e il suicidio assistito si collegano, nella opinione dei proponenti, a diritti tutelati costituzionalmente, come l'integrità fisica e morale della persona, la dignità umana, il valore superiore della libertà, la libertà di coscienza o il diritto alla privacy.

Nel preambolo della proposta di legge se ne leggono i motivi informatori. La legalizzazione e la regolamentazione dell'eutanasia si basano su alcuni principi essenziali che sono alla base dei diritti delle persone e sono inclusi nella Costituzione spagnola. Sono, da un lato, i diritti fondamentali alla vita e all'integrità fisica e morale, e dall'altro, i valori costituzionalmente protetti come la dignità, la libertà o l'autonomia della persona. La proposta di legge impone garanzie sufficienti a salvaguardare la libertà assoluta della decisione, escludendo qualsiasi pressione esterna. Il contesto eutanasico, in cui è legalmente accettato l'atto di aiutare un'altra persona a morire, deve essere circoscritto e limitato a determinate condizioni che riguardano la situazione fisica e mentale in cui la persona si trova. Allo stesso modo, le garanzie devono essere stabilite in modo tale che la decisione di porre fine alla vita avvenga in assoluta libertà, autonomia e conoscenza, protetta da pressioni di ogni tipo che potrebbero provenire da ambienti sociali, economici o familiari e da decisioni affrettate. Questo contesto eutanasico, così delimitato, richiede una valutazione qualificata e indipendente, prima e dopo l'atto eutanasico. Allo stesso tempo sono garantiti la sicurezza legale e il rispetto della libertà di coscienza del personale sanitario chiamato a collaborare all'atto di aiutare a morire.

La proposta di legge ricalca la legge belga migliorandola sensibilmente e omettendo alcune delle contraddizioni e incoerenze riportate nella sezione di questa Appendice relativa al Belgio. Il principale miglioramento è il controllo *a priori* da parte della Commissione di controllo. Tra le incoerenze che non sono eliminate, segalo: non ci sono misure per tracciare le eutanasie clandestine né sanzioni per il medico che non trasmette il rapporto alla commissione di controllo; non è prescritta una procedura per la scelta del secondo medico chiamato a consulto e il suo parere non è che consultivo.

Al momento di andare in stampa (primavera 2020), la proposta di legge approvata dal *Congreso de los Diputados* deve ancora essere discussa dal *Senado de España.*

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## Svizzera

Il suicidio assistito è permesso in Svizzera (9 milioni di abitanti) se non è motivato dall'interesse personale. Il Codice penale confederale non contiene alcuna disposizione esplicita che disciplini l'eutanasia né la sospensione o l'interruzione di azioni per prolungare la vita e la gestione del sollievo dal dolore, un cui effetto collaterale può essere di accorciare la vita. Il Codice Penale, tuttavia, proibisce l'uccisione per qualsiasi motivo, stabilendo così una linea chiara tra interventi medici punibili e non punibili[xxx]. Il legislatore della Confederazione elvetica ha scelto di non proporre disposizioni più specifiche per definire le circostanze in base alle quali un atto il cui esito finale è di terminare o accorciare la vita sia o meno punibile. La motivazione è basata sul criterio che qualsiasi decisione di carattere generale non avrebbe compiutamente affrontato tutte e ciascuna delle questioni critiche sollevate in ogni caso specifico e non avrebbe pertanto apportato alcun vantaggio pratico. I codici di condotta professionali, al contrario — come le linee guida dell'Accademia svizzera delle scienze mediche[xxxi] o le deliberazioni dei comitati etici degli ospedali o del servizio sanitario confederale — sono più adatti a trattare in dettaglio le molteplici complessità di questi casi.

Le fonti di finanziamento per le cure palliative sono miste in Svizzera: 30 per cento dei finanziamenti proviene da fondi pubblici, 30 per cento da organizzazioni non lucrative di utilità sociale (ONLUS) e 40 per cento da organizzazioni private[xxxii].

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## United States of America

In the American healthcare system there is no single government provider since the organization consists of several tiers set within a federal system of government.[65] Government healthcare roles are at federal, state and local level.

In the United States, hospice programmes began in the l970s, and Medicare funding was secured in l982 (providing reimbursement of costs through insurance, but requiring relinquishment of curative treatments).[66]

## Palliative care services and hospice care

Today, palliative care is a central part of treatment for serious or lifethreatening illnesses.[67] Ideally, palliative care should be initiated concurrently with a diagnosis of a serious illness and at the same time as curative or diseasemodifying treatments, given the near universal occurrence of patient and family distress and their need for information and support in establishing achievable goals for the patient's medical care. The National Institute of Health (NIH) informs citizens to help them understand how patients or someone close to them can benefit from this type of care. The NIH defines palliative care as the comprehensive treatment of the discomfort, symptoms and stress of a serious illness. Palliative care does not replace the patient's primary treatment and works together with it, providing relief from distressing symptoms, among them pain, shortness of breath, fatigue, constipation, nausea, loss of appetite and problems with sleep. It can also help patients deal with the side effects of the medical treatments they are receiving. Perhaps most importantly, palliative care can help improve the quality of life for patients and their families alike.

Palliative care is different from hospice care, which focuses on a person's final months of life. Contrary to the meaning of hospice care in Europe (where it is intended as patient care in a particular setting, namely the hospice), hospice care in the US is a model of quality, compassionate care for people facing a lifelimiting illness that is offered in the patient's home, but may also be provided in independent hospice centres, hospitals, nursing homes, or other longterm care facilities.[68]

Palliative care also provides support for a patient's family and can improve communication between patients and their healthcare providers, as well as offering emotional and spiritual support for both. Palliative care is provided by a team of specialists who may include palliative care doctors, palliative care nurses, trained volunteers, social workers, chaplains, pharmacists, nutritionists, counsellors and others. The Palliative Care Provider Directory of Hospitals helps in searching for a hospital that offers a palliative care programme in any US state and city.[69]

Hospice services are available to patients with any terminal illness, regardless of age, religion or race. Members of the hospice staff make regular visits to assess the patient and to provide additional care or other services. Hospice staff are on call twentyfour hours a day, seven days a week. The hospice team develops a care plan that meets each patient's individual needs for pain management and symptom control. The National Hospice and Palliative Care Organization (NHPCO) estimates that in 20l2, 400,000 hospice volunteers provided l9 million hours of service, spending time with patients and families, providing clerical and other services, and helping with fundraising efforts.

In 20l3, the number of deaths in the US was 2.6 million out of a population of 32l million. The percentage of US deaths served by hospice care is 6l per cent and steadily increasing over the years.[70] In 20ll, the average length of hospice care was l8.7 days, and a few patients received more than l80 days of care. Until recently, palliative care services were typically available only to patients enrolled in hospice centres. Now, however, in addition to other settings, palliative care programmes are found increasingly in hospitals, which are a main location for the care of the seriously ill and, on average, the place of death for 50 per cent of adults nationwide. In 2009, 62 per cent of US hospitals with at least 50 beds and 84 per cent of hospitals with more than 300 beds reported having a palliative care programme, which is an increase of l34 per cent since 2000.[71]

## Where palliative care is provided

The majority (96.5 per cent) of patient care is provided in the place the patient calls 'home'. In addition to private residences, this includes nursing homes and residential facilities. In 20l2, 66 per cent of patients received care at home. The percentage of hospice patients receiving care in a hospice inpatient facility was 27 per cent.

Hospice services in the US developed from the New Haven, CT organization, founded in l974, to some 3,000 US hospices at the turn of the century.[72] Dame Cicely Sanders, the founder of St Christopher's Hospice in London, lectured from coast to coast in the US on pain management and total care for the dying from l963 onwards, and doctor Elisabeth KuiblerRoss had been running seminars on the dying at the Billings Hospital in Chicago, IL, since 1969. In the US today, the focus on home care and the idea of hospital teams and inpatient hospice beds is less developed than in other Western countries. A major milestone in 1982 was the achievement of funding recognition for hospices under the US Medicare programme.

Access to palliative care and hospice programmes is widely variable across the country. Forprofit hospitals, hospitals in the southern US, and small, safety net hospitals (fewer than 100 beds) are less likely to report hospital palliative care programmes compared to notforprofit hospitals, hospitals outside the South, and larger hospitals. Access to hospice care is also highly variable. Based on 2006 data, it covered as low as 6.7 per cent of all deaths in Alaska, to as high as 44.7 per cent of deaths in Arizona.[73]

## Legal aspects

In 1973, some twenty years prior to the publication of the Patient's Charter in England,[74] the American Hospital Association published the Patient Bill of Rights, the first document in America to express the rights of patients while in hospital.[75] The Patient Bill of Rights was used to express what all patients should expect in hospital, while at the same time providing a tangible means by which hospitals could express their commitment to their patients. The document had a strong influence on hospitals throughout America and ultimately influenced many states to develop their own distinctive patient rights bills. One of the best examples is the State of New Jersey Patient Bill of Rights, adopted in the late 1980s.[76] Patients rights include, but are not limited to, the right of access to care; the right to be treated without discrimination; the right to be introduced to any healthcare provider by name in addition to the use of a name badge; the right to receive confidential treatment; the right to personal medical records and the procedure for gaining access to them; the right to give informed consent; the right to refuse medical care with knowledge of the consequences; the right to decline participation in medical research or medical training; the right to be informed of the facility's policies and procedures regarding the withdrawal and withholding of life support; and the right to be informed of the entitlement to have care transferred from a practitioner or facility and the procedure to accomplish this.

The New Jersey Patient Bill of Rights provides a strongly visible public commitment by all the parties concerned regarding the rights of the patients it serves. This, coupled with an accessible and enforceable mechanism of redress for patients who feel they may have been wronged or had their rights violated, signifies that the strategy is working. The Bill expresses a strong, universal commitment to the rights of all patients, and this has resulted in further advocating for individuals with special needs or challenges. For example, deaf patients must be provided with their preferred means of communication.[77]

In October 1997, the US state of Oregon legalized physicianassisted suicide (PAS). Since then, many states have rejected assisted suicide measures -some of them multiple times -whereas the states of Washington, Vermont, New Mexico and Montana all legalized PAS between 1997 and 2013. California might soon be added to the list: California senators gave final approval on a 23-14 vote after an emotional debate on 11 September 2015 to a PAS bill that would allow terminally ill patients to legally end their lives. The measure faces an uncertain future because the Governor might not sign the act. The measure to allow doctors to prescribe lifeending medication succeeded on its second attempt; it includes requirements that the patient be physically capable of taking the medication themselves, that two doctors approve it, that the patient submit several written requests, and that there be two witnesses.[78] In the US states that have legalized PAS, only residents of those states are allowed access to legal suicide assistance.

Euthanasia remains illegal in all US States.[79] Debates about euthanasia raged in the United States at the turn of the nineteenth century, which resulted in an 1906 Ohio bill to legalize euthanasia that was ultimately defeated.[80] Euthanasia advocacy in the US peaked again during the 1930s, only to diminish significantly during and after World War II. Euthanasia efforts were revived during the 1960s and 1970s under the righttodie rubric, physicianassisted death in liberal bioethics, and through advance directives and donotresuscitate orders. The inflammatory nature of US debates on the subject has highlighted the biggest cultural barrier to delivering palliative and hospice care -the fact that people associate such care with dying rather than with providing quality of life when suffering terminal illness. Proponents of euthanasia have presented four main arguments:[81]

1. to recognize a right to selfdetermination, allowing to choose one's own fate;
2. to assist patients to die might be a better choice than requiring that they continue to suffer;
3. to distinguish between euthanasia and withdrawal or withholding treatment;
4. to reassure that permitting euthanasia will not necessarily lead to unacceptable consequences.

In the US, discussion of endoflife care often inflames religious sentiment that holds the sanctity of life paramount. The issue is complicated by the perception that hospice care is often associated with giving up. Opponents to a legal right to euthanasia or assisted suicide typically appeal to three arguments: a 'slippery slope' argument (society will be inexorably led to permit further unethical actions); an argument about the dangers of practising euthanasia beyond the tight boundaries established by the law; and the above mentioned argument about the sacred and nondisposable value of human life. Elisabeth KuiblerRoss, an eminent SwissAmerican psychiatrist, opposed euthanasia in her seminal book, On Death and Dying And The Five Stages of Grief (l969) and encouraged the hospice care movement, believing that euthanasia would prevent people from completing their 'unfinished business'.[82]

## Cost of palliative care

Financial concerns can be a major burden for many patients and families facing a terminal illness. The federal administration exercises a large financial role through Medicare, a national social insurance programme that provides health insurance for Americans aged 65 and older who have worked and paid into the system. The federal administration sets standards for Medicare providers and determines what drugs may be sold, while the insurance industry and health codes are regulated at state or local level. Medicaid, a social healthcare programme for families and individuals with low income and limited resources, also funds endoflife care. It is jointly paid for by the state and federal governments and managed by the states. In addition to Medicare and Medicaid, most private insurance plans cover hospice care.

The Medicare Hospice Benefit[83] enacted by Congress in 1982 is the predominate source of payment for hospice care. In 2012, 83.7 per cent of hospice patients were covered by the Medicare Hospice Benefit. Other payment sources are the Medicaid Hospice Benefit,[84] the Health Maintenance Organization,[85] other managed care organizations and most private health insurance plans. If patients do not have insurance or their insurance does not cover hospice care, they are still entitled to contact a hospice. However, those not yet eligible for Medicare and not sufficiently poor to qualify for Medicaid must either rely on private health insurance, convert their life insurance policies to help pay for hospice treatment, or find other sources of funding. While each hospice has its own policies concerning payment, it is a hospice tradition to offer services based on need rather than on the ability to pay.[86]

Estimates show that about 27 per cent of Medicare's annual budget ($88 billion out of a total $327 billion in 2006) goes to care for patients in their final year of life.[87] A wellestablished network of nonprofit hospices in the US plays an important role in cutting National Health Service expenditure.

Vai indietro all'Indice

# Canada

## Background

Palliative care was introduced in Canada forty years ago to meet the needs of people with an incurable disease that seriously compromised their survival.[88] It evolved following a unique care philosophy that takes a holistic approach, offering new outlooks and including a series of measures to humanize care for endoflife patients and their families.

Canada has set up a national strategy on palliative and endoflife care,[89] but one weakness in its provincially administered universal healthcare system is the lack of a nationwide standard for palliative care,[90] which generates nonhomogeneous approaches and different levels of provision across the country.[91] Although Canada is geographically large, it has a population of fewer than 34 million people: hospice and palliative care services reflect the size of the population, yet they cannot cover the entire country.

The Canadian Palliative Care Association reaffirms the values intended to guide palliative care services:[92]

- The intrinsic value of each person as a unique individual, the value of life, and the inescapable nature of death.
- The necessary participation of patients through their free and informed consent to ensure they are party to decisions in accordance with their wishes on all matters concerning them, including their true condition, and that their choices are respected.
- The duty of confidentiality on the part of caregivers, which prevents the release of personal information without patient authorization.
- The right to compassionate caregiver services respectful of what provides meaning to people's lives -their values, culture, beliefs, and religious practices and those of their families.

Like many Western societies, the Canadian population will age quickly in the coming decades. For example, the number of people aged 65 or over,

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which was l3 per cent in 200l, will reach 25 per cent in 2036 and 30 per cent in 204l. This fact will have sizeable repercussions on the health and social services needs of endoflife patients.

This trend will lead to an increase in the number of people with progressive and often chronic diseases that require endoflife palliative care. Canadian society is faced with the challenge of dealing with a large number of deaths in a very short period of time, with all the resulting psychological and social consequences.

## Palliative care services and hospice care

In l975, a palliative care unit was opened at the St Boniface Hospital in Winnipeg, Manitoba, and weeks later, in l976, a similar palliative care unit was opened at the Royal Victoria Hospital in Montreal, Quebec, by doctor Balfour Mount. Dr Mount, a pioneer in hospice/palliative care, introduced the term 'palliative care' rather than 'hospice' because in Canadian historical culture the word hospice was commonly associated with a place of last resort for the poor or derelict. In l976 the First International Congress on the Care of the Terminally Ill was held in

Montreal, and was organized thereafter every two years by doctor Mount and his colleagues.

Canada continues to be a leader in hospice/palliative care, in part because of a strong policy framework that has underpinned the development of services, and the environment within which those services operate.

The Palliative Care Foundation in Toronto, Ontario, released an official definition of hospice palliative care in I98I, stating that, 'Palliative care is active compassionate care of the terminally ill at a time when their disease is no longer responsive to traditional treatment aimed at cure and prolongation of life and when the control of symptoms, physical and emotional, is paramount. It is multidisciplinary in its approach and encompasses the patient, the family and the community in its scope.' Two years later, the University of Ottawa, Ontario created Canada's first university institute for research and education in palliative care. The Canadian Palliative Care Association was established in November I99I and opened its first office in Ottawa in February I994. The organization later changed its name to the Canadian Hospice Palliative Care Association (CHPCA), due to hospice care and palliative care being recognized as one and the same. Since I98I, the British Columbia Ministry of Health has supported a community palliative care project, starting with an inpatient unit at the Royal Jubilee Hospital in Victoria, BC, and the second unit at Vancouver, BC, General Hospital. The BC Ministry of Health has also provided home care support to enable terminally ill patients to remain in the comfort of their own homes. However, in general, hospice programmes must raise their own funds in their communities to financially support their individual programmes.

## Where palliative care is provided

In Canada, due to the tendency to prefer home death, health system restructuring has led to a greater focus on homebased palliative care as an alternative to institutionalized palliative care.

Palliative care is offered in various organizational settings:

- Community based hospice palliative care This type of programme has no special facility of its own other than an office. The programme centres around the patient, whether they are at home or in a healthcare facility. A multidiscipline team approach is used to provide physical, emotional and spiritual support for the patient and the family.

- Hospital based A unit within the hospital is specifically allocated for terminally ill patients to die in if they so choose, as well as for symptom management and respite. The unit may have either a totally independent staff or personnel who rotate from the main hospital.
- Hospitalbased team This team has no designated place within the hospital, but there will be a specific number of designated beds scattered throughout the hospital to be used for palliative care patients. Patient care is administered by the regular ward staff, and the team sees the patient on a daily basis, making suggestions for care as they assess the needs.
- • Hospice Bed
- This is a bed designated in a location elsewhere than a hospital. The multidisciplinary team used for the community base is utilized here as well.
- Freestanding hospice The freestanding hospice is housed in its own building and served by a multidisciplinary team.

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The Canadian Hospice Palliative Care Association (CHPCA) publishes online the Canadian Directory of Hospice Palliative Care Services.[93] This online directory has been designed to provide Canadian citizens with information on the availability of hospice palliative care services across Canada. The directory provides a provincebyprovince listing of programmes and services, contact information for these, and where they provide care. The International Association for Hospice & Palliative Care (IAHPC) publishes online a Global Directory of Palliative Care Services) Hospices and Organizations, where citizens can find information on palliative care service providers associations and umbrella organizations. Such information is gathered by IAHPC from voluntary submissions from the service providers' organizations.[94]

## Legal aspects

In federal Canada, euthanasia at the time of writing is illegal and is considered as murder. Suicide is not a crime in Canada and has not been such since 1972, but physicianassisted suicide is illegal. In February 2015 a decision by the Supreme Court of Canada struck down the provision prohibiting assisted suicide, though the ruling does not take effect until 2016.[95]

However a new law decriminalizing euthanasia (Bill 52, 'An Act respecting endoflife care')[96] is due to come into force on 10 December 2015 in Quebec, unless the federal government challenges it. Bill 52 was passed in June 2014 in the

Quebec National Assembly in a 94-22 free vote. The purpose of this Act is to ensure that endoflife patients are provided care that is respectful of their dignity and their autonomy, and to recognize the primacy of wishes expressed freely and clearly with respect to endoflife care. It sets out special rules applicable to the providers of endoflife care; that is, institutions, palliative care hospices and private health facilities, in order to provide a framework for the organization and regulation of endoflife care. In this respect, it specifies the special functions and powers of health and social services agencies and of the Quebec Minister of Health and Social Services. It also establishes specific requirements for certain types of endoflife care: namely, continuous palliative sedation and medical aid in dying. The latter is in fact euthanasia, although this word is not mentioned in the text of the Act. Medical aid in dying is defined as 'care consisting in the administration by a physician of medications or substances to an endoflife patient, at the patient's request, in order to relieve their suffering by hastening death'. The Act prescribes the criteria that must be met for a person to obtain medical aid in dying and the requirements to be complied with before a physician may administer it.

A commission on endoflife care has been established under the title Commission sur les soins de fin de vie [Commission on endoflife careJ, as well as rules with respect to its composition and operations. The mandate of the Commission is to examine all matters relating to endoflife care, and to oversee the application of specific requirements relating to medical aid in dying.

The Act establishes an advance medical directives regime and specifies the conditions that must be met in order for such directives to have binding force.

## Cost of palliative care

In the current environment of rising healthcare costs and concerns about the sustainability of publicly funded healthcare, policymakers are paying more attention to the costs associated with the final year of life. The cost of dying in Canada incurred by the healthcare institutions ranges from as low as $l0,000 for a sudden death to between $30,000 and $40,000 for someone with a terminal disease such as cancer or chronic obstructive pulmonary disease. The cost of dying varies not only by cause but also by where people die: on average it costs

$36,000 to die in a chronic care facility, compared to $16,000 to die at home.[97] This is due to changes in the distribution of costs borne by different stakeholders, whereas the estimated total societal cost of endoflife care shows no significant difference because hospitalization costs for hospitaldeath patients were replaced by higher, unpaid caregiver time, and outpatient service costs for homedeath patients.[98] Developing better palliative and home care services could significantly reduce overall societal costs.[99]

Most of these endoflife costs are absorbed by the healthcare system, although families also experience substantial caregiving and outofpocket costs. Hospice palliative care services can reduce the costs of dying and improve patient care. They can significantly reduce the healthcare costs of patients who are dying by reducing hospital admissions, the length of hospital stays, readmissions, visits to intensive care units, and inappropriate diagnostics or interventions.

Hospitalbased palliative care reduces the cost of endoflife care by 50 per cent or more in comparison to the cost of care provided in conventional internal medical wards. Primarily, this is done by reducing the number of intensive care unit admissions, diagnostic testing, interventional procedures and overall hospital length of stay.

In 2012, only 1630 per cent of Canadians had access to or received hospice palliative and endoflife care. Threequarters of deaths still occur in hospitals and longterm care facilities rather than taking place at home, which most Canadians would prefer. Improved and more equitable access to hospice palliative care could not only save the Canadian healthcare system millions of dollars each year but also enhance care and quality of life for patients and families.

Vai indietro all'Indice

# Ireland

## Background

As early as the twelfth century, monastic societies founded hospitals within their walls to care for the sick. Communities outside cloister walls imitated this and built hospitals. As science and medicine developed further, especially anatomy and surgery, care began to concentrate on cure. However, monks and nuns continued to care for those for whom cure was not an option. Sister Mary Aikenhead (l787-l858) from Cork, Ireland, founder of the Congregation of the Religious Sisters of Charity, opened Our Lady's Hospice (l845) as a charitable and religious mission to care for those dying of tuberculosis and living in poverty. The Congregation established Our Lady's Hospice in Harold's Cross, Dublin, in l879. New buildings were added, including a night school for women and girls and a Sunday school. Throughout the twentieth century there were further developments, including palliative care facilities for the hospice.

## Palliative care services and hospice care

Palliative care is provided in Ireland by the Health Service Executive Ireland (HSE), to people of any age and at any stage of their illness, in order to better manage symptoms and complications when undergoing, for example, treatments such as chemotherapy. Each healthcare team has three levels of palliative care provision representing increasing specialization:

Level l: in any location or setting all healthcare professionals, as part of their role, use a palliative care approach. Level 2: in any location, healthcare professionals with additional and specialized knowhow practise a palliative care approach. Level 3: in a hospice or specialized hospital ward, healthcare professionals with extensive knowledge and skills work solely in palliative care.

The hospice is a specialist unit that provides palliative care. There are ten inpatient hospices in Ireland offering inpatient or outpatient day care. The hospice mainly treats patients with illnesses that cannot be cured. Many people who receive hospice care have cancer, but hospices also treat patients with other conditions. Patients are referred to the hospice as inpatients for the following reasons:

1. To control symptoms: for example, pain or nausea.
2. To provide temporary respite for patients and their carers.
3. For rehabilitation purposes. Services such as physiotherapy, occupational therapy, complementary therapies and dietetics may be available to assist in improving patients' wellbeing and quality of life.
4. For endoflife care.

## Where care is provided

It is important to enable people to die where they prefer. Patients most commonly express a wish to die at home, but in addition to preference, a number of factors also influence the place of death. When a seriously ill, hospitalized patient does express a wish to die at home their request is not simply viewed as impractical or impossible. Rather, a realistic evaluation of the feasibility of different options is undertaken. The HSE facilitates this by promoting collaborative working and effective communication across primary and secondary care to ensure a safe, smooth and seamless transition of care from hospital to community for patients with terminal illnesses who choose to be cared for in their own home during their last days of life.

Palliative care can be arranged by the family doctor (GP) or by the hospital the patient is attending. Palliative care is provided in the following settings:[100]

- General hospitals, by the specialist palliative care team.
- A person's own home, by specialist palliative care nurses who work with the patient's family doctor, the specialist palliative care team and the public health nurse.
- Community hospitals and nursing homes, by specialist palliative nurses who work with the patient's family doctor and/or a specialist palliative care team.
- The Inpatient hospices.

Citizens seeking to arrange palliative care can call the free phone number (1800 200 700) and speak in confidence to a specialist nurse.

## Legal aspects

Both euthanasia and assisted suicide are illegal under Irish law. Depending on the circumstances, euthanasia is regarded as either manslaughter or murder and is punishable by sentences up to life imprisonment.

It is not, however, illegal to remove life support or to withhold or withdraw other treatment, should a person or their next of kin request it. A September 2010 Irish Times poll showed that a majority of 57 per cent of adults believed that physicianassisted suicide should be legal for terminally ill patients who request it.[101]

In Ireland, there is no legislation which provides for the recognition and enforcement of an advance care directive, also known as a 'living will', which is a statement about the type and extent of medical or surgical treatment patients may or may not want in the future on the assumption that they might not be able to make that decision for themselves at the relevant time. This does not necessarily mean that these advance care directives are not valid, but it does mean that information and guidance from other jurisdictions might not apply.

Patients cannot give anyone else any legal right to make decisions on their behalf about their healthcare, should they be incapable of doing so themselves, but they may suggest to their doctor or hospital that the wishes of certain people should be taken into account. However, they cannot be assured that the doctor or hospital will abide by their wishes.

If a healthcare issue arises and the patient is incapable of making a decision, it is the practice to consult with next of kin. It is not clear what legal basis supports this, given that next of kin have no right to make decisions on behalf of adults. Medical ethics currently in force in Ireland state that consultation with next of kin is desirable if the patient is unable to make a decision or to communicate, and it provides for a second opinion if there is a difference of opinion between the patient's family and the doctor. Next of kin are (in order) spouse, children, parents and siblings. Partners have no legal status and may even experience difficulties in visiting patients if family members object. This is the case whether the patient is in either a heterosexual or a homosexual relationship.[102]

## Cost of palliative care

In Ireland, everyone is entitled to public hospital care. Despite this, the number of citizens purchasing private health insurance has continued to grow to the point that about 40 per cent of the population now has private health insurance. This is due to perceived concerns (often unfounded) about waiting times for public care and the quality of that care.[103] The cost of supplying palliative care in Ireland is on a par with care provided in comparable acute settings; the average yearly hospice bed cost for 2010 was €718 per day for specialist inpatient units, while the €262,000, while the average cost of an acute hospital bed was €909 per day.[104]

The delivery of palliative care services in Ireland is heavily reliant on the voluntary sector. As an example, Galway Hospice Foundation is a voluntary organization established in I986.[I05] It has been awarded accreditation by Caspe Healthcare Knowledge Systems and received ISO 900I:2008 certification. The Galway Hospice depends on the generosity and goodwill of the public to fund the Home Care Service (available 7 days a week, 365 days a year), Day Care Service, Bereavement Support Service and Educational Facility. Altogether, the provision of these services costs in excess of €1.6 million per annum.

While the majority of patients cared for by the Galway Hospice team express the wish to remain at home, and with the support of the Home Care Service are able to do so, there are patients who, for a variety of reasons, cannot. Some patients' symptoms may be difficult to control in the community, carers may need a period of respite, and sometimes patients may not have adequate support systems to allow them to remain in their own homes throughout their illness.

In order to meet the needs of such patients, in I992 the Galway Hospice Foundation set about raising the capital cost for a purposebuilt facility incorporating inpatient, day care and support services. The cost, which was approximately €C2.6 million (a very sizeable sum at that time), was raised solely through voluntary donations from the community, businesses, the farming and professional sectors of Galway city and county, and individual donations from far and wide.

In I997, funding from the Western Health Board (now HSE West) was approved for the running costs of the Inpatient Unit, allowing the first patients to be admitted in December of that year. Patients are admitted for symptom control, respite, psychological support and endoflife care, or a combination of these. The usual length of stay is approximately two weeks.

When Irish citizens with a cancer diagnosis experience financial difficulty, yet find themselves unable to benefit for whatever reason from schemes such as social welfare support, they may apply to Financial Aid, a hardship fund set up by the Irish Cancer Society to help patients and their families in covering costs they cannot face, such as home heating, child care or respite.

Vai indietro all'Indice

# Australia

## Background

Healthcare in Australia is provided by both the government and private institutions. The Federal Minister for Health administers national health policy, elements of which are operated by individual state governments. Australia is a highincome country, and this is reflected by the population's general good status of health. Life expectancy in Australia is among the highest in the world. Despite this high standard of health, certain disparities in the Australian healthcare system are a problem. The poor, those living in remote areas and the indigenous population are, in general, less healthy than the rest. The Australian Institute of Health and Welfare noted that compared with the inhabitants of major cities, people in regional and remote areas were less likely to report excellent or very good health, with life expectancy decreasing with increasing remoteness. Programmes have been implemented to reduce this gap. These include increased outreach to the indigenous communities and government subsidies to provide services for people in remote or rural areas, and for people belonging to nonEnglishspeaking groups.[106] A desire to educate the community about palliative care falters at the doorstep of nonEnglishspeaking groups. The inability of some Australians to read English is merely the first stumbling block. Cultural attitudes and traditions create a tricky path, requiring delicate steps. The fact that the words death, dying and cancer are taboo for many cultures creates immediate difficulties in discussing palliative care.[107]

With regard to endoflife care, the situation in Australia presents a number of differences across geographical areas, given that the institutions of the various Australian states can legislate autonomously on these matters. Territories are in a different position. Unlike the states, which are sovereign entities possessing legislative power in their own right, a territory's legislative power is derived through a grant issued by the Commonwealth Parliament, which still retains the power -in practice very rarely exercised -to legislate for the territory. The level of endoflife care is, nevertheless, at the highest level of world standards throughout the country.

Whilst there is a National Palliative Care Programme that supports national approaches, most palliative care service provision occurs within the remit of the state and territory health systems. Each state and territory has an articulated approach to palliative care in its jurisdiction. The National Palliative Care Strategy is intended to provide the framework for the Commonwealth, states and territories to work together cooperatively and collaboratively.[108]

Different service sectors adhere to a number of distinct definitions for palliative care. The Commonwealth recognizes that state and territory jurisdictions work under varying definitions. Each regional jurisdiction has articulated its definition in its strategic documents. The Palliative Care Intergovernmental Forum adopted the WHO definition reported earlier in this appendix as the national definition of palliative care.

## Palliative care services and hospice care

Palliative care usually consists of medication and treatments, medical reviews and assessments, help and guidance with accessing information and resources, shortterm care relief and respite care, counselling and emotional support, and bereavement support for carers and family after a patient's death. Palliative Care Australia, the national organization representing all state and territory palliative care organizations, says that a palliative approach is used by primary care services and practitioners to improve the quality of life for individuals with a lifelimiting illness, and for their caregivers and family. The palliative approach incorporates a concern for the holistic needs of patients and caregivers, which is reflected in the assessment process, in the primary treatment of pain, and in the provision of physical, psychological, social and spiritual care. Application of the palliative approach to the care of an individual is not delayed until the final stages of their illness. Instead, it provides a focus on active, comfortoriented care and a positive approach to reducing suffering and promoting understanding of loss and bereavement in the wider community. Underlying the philosophy of a palliative approach is the view that death, dying and bereavement are all an integral part of life.

Over the last twenty years in Australia, the palliative care specialization has advanced considerably.[109] A global comparative study of endoflife care conducted by the Economist Intelligence Unit gave the highest ratings to Australia (and the UK) out of 40 countries studied.[110] The two countries received a rating of 7.9 out of 10 in an analysis of access to services, quality of care and public awareness.

The idea of a good death held by hospice and palliative care practitioners is changing in Australia. Palliative care practitioners are searching for an ideology to inform their practice within the context of a complex society for which there is no 'one' good death, reflecting the uncertainties held by many Australians. The good death ideology of the original hospice movement proposed a manner of dying in which open communication and acceptance of death were actively encouraged. This model, however, has become increasingly inappropriate in the current climate of patient autonomy and consumer choice. A practice of palliative care, which follows the ethic of individual choice, has emerged from and replaced the original hospice movement.[111]

Within Australia, palliative care is provided across the health and human services spectrum by public hospitals, private hospitals, hospices, general practitioners, justice health services, disability services and specialist palliative care services -both public and private -in inpatient as well as communitybased settings. Specialist palliative care services operate from a variety of settings, including specialist inpatient consulting services, specialist inpatient settings, hospices and communitybased specialist services. Specialist palliative care comes into play when people experience severe or complex problems as their condition advances. These individuals can then be referred to a specialist palliative care service where a team of specialist professionals will work to meet their needs. Alternatively, general practitioners may seek advice from specialist palliative care services on their patients' behalf.

## Where care is provided

Hospices and palliative care services for inpatients and patients at home are available nationwide. Some of these services are offered by nonprofit organizations. Palliative care service provision occurs within the remit of the state and territory health systems. For information on who to contact regarding palliative care service provision in a particular area, the patient's family can consult a GP, hospital or health centre for more specialized support, or visit the National Palliative Care Service Directory online.[112]

The Australian Government also provides information on what to do following a death, including information about financial matters, who to notify, and relevant payments and services.

Remaining at home is the preferred choice of most people when they age and most healthy Australians, when asked where they would prefer to die, nominate their home as their wish. Help is provided for older adults to either stay at home or to be discharged as soon as possible from hospital or rehabilitation beds. For the infirm, living at home may necessitate safety and convenience measures, such as making bathrooms accessible and safe, fitting stair lifts and placing handrails in corridors. Living at home is made easier by the Community Support Services, which offer meals, social and transportation services, adult day care, Senior Centres, personal homecare services and nursing care.

However, the statistics on place of death indicate that a home death is relatively uncommon; only 16 per cent of people die at home. Twenty per cent of people die in hospices and 10 per cent in nursing homes. The rest die in hospitals. This results in a high financial burden on the health system and a potentially poorer quality of death.

## Legal aspects

Currently, euthanasia and physician assisted suicide are illegal in Australia; to assist with euthanasia is also a crime, although prosecutions have been rare. The closest euthanasia has come to being legalized by a state was in Tasmania in 2013 when an Australian Greens party voluntary euthanasia bill was narrowly defeated in the Tasmanian House of Assembly by a vote of 13 to 12.

Euthanasia and physician assisted suicide had previously been legalized in Australia's Northern Territory by the Rights of the Terminally Ill Act) approved by the NT Parliament in 1995, at a time when no such bill had been adopted anywhere else in the world. The act allowed, under strict conditions, terminally ill patients to commit physician assisted suicide or ask for euthanasia, either by the procurement of drugs or by the direct involvement of a physician administering the lethal substance to the patient.[113] It required a somewhat lengthy application process, designed to ensure that patients were both mentally competent to make the decision and in fact terminally ill. It passed by a vote of 15 to 10 during the year 1995 and came into force in July 1996. Only nine months later, in March 1997, the law was voided by the federal Euthanasia Laws Act 1997.[114] However, four people had already died under the legislation through physicianassisted suicide.[115] The law had applied to all Australian citizens, and one resident from South Australia did take advantage of it.

The Euthanasia Laws Act 1997 has no effect on the power of an Australian state to pass any law permitting euthanasia, and it expressly leaves open the possibility of a territory passing laws regarding the withholding of life support.

Public debates held about euthanasia and physician assisted suicide raised awareness and gained strong media attention. Pressure brought on policymakers over these issues has been a catalyst for the improvement of palliative care services. In fact, the federal overturning of the NT euthanasia law of 1996 led to increased national funding for endoflife care.

Advance Health Directives are legal documents in Western Australia and in other states and territories. With Advance Health Directives, capable adults can set out their decisions about what kind of treatments they agree or do not agree to, including withholding or withdrawing life sustaining treatments and artificial feeding. An Advance Health Directive can come into effect if, later on, the person is no longer able to make competent judgements about their treatment. Advance Care Planning also includes communicating an individual's views, preferences and decisions about their future care, such as where they would like to be cared for when dying, and what kind of funeral would they prefer.

Guidelines for withholding and/or withdrawing life sustaining measures, including artificial feeding, have been produced by several states.[116] These identify principles that apply to decision making and quality care at the end of life, and focus on considerations about ethical and special matters, such as decision making for people who are incapable of deciding for themselves.

## Cost of palliative care

Healthcare in Australia is universal. In 1988, palliative care was enshrined in the Australian healthcare agreements, through which the federal government funds expenditures on behalf of the country's states and territories. In the financial year 20ll-20l2, the national health system was financed at 9.5 per cent of GDP. The federal government pays a large percentage of the cost of services in public hospitals, typically covering l00 per cent of inhospital costs, 75 per cent of general practitioner costs and 85 per cent of specialist services. Most home care is government funded. Under the Original Medicare Safety Net, once the annual threshold of patient outofpocket expenses for nonhospital Medicare services has been reached, the Medicare benefit is increased to l00 per cent (up from 85 per cent) for the remainder of the calendar year. The Extended Medicare Safety Net, introduced in 2004, provides an additional payment for nonhospital Medicare services once an annual threshold of patient spending is reached. Out-of-pocket costs represent the difference between the Medicare payment for treatment and the fee the practitioner charges the patient. Once patients' outofpocket threshold is reached, for the remainder of the calendar year they receive 80 per cent of outofpocket costs in addition to the standard Medicare payment.

Medicare, instituted in l984, is the publicly funded universal healthcare system in Australia. It coexists alongside a private health system. Medicare is funded partly by an income tax surcharge known as the Medicare Levy, which is currently set at 2 per cent of a person's taxable income (with exceptions for lowincome earners), with the balance provided by the government from general revenue. An additional levy of I per cent is imposed on highincome earners without private health insurance. As well as Medicare, there is a separate Pharmaceutical Benefits Scheme that considerably subsidizes a range of prescription medications.

In circumstances where the government pays a large subsidy on costs, the patient pays the remainder unless the provider of the service decides otherwise and leaves the patient with nothing to pay. The Australian Government's Department of Human Services delivers a range of payments and services supporting people in need. Such provisions include respite services, which assist families in caring for family members with physical disabilities, thus enabling them to stay together as a unit.

Where a particular service is not covered, patients must pay the full amount unless they hold a Low Income Earner card, which may entitle them to subsidized access. Individuals can take out private health insurance to cover outofpocket costs, subscribing either to a plan that covers certain selected services or to a full coverage plan. The Australian government has introduced a number of incentives to encourage adults to take out private hospital insurance.

Vai indietro all’Indice

# New Zealand

## Background

Palliative care is a crucial part of New Zealand's healthcare system, providing care and support for people with lifelimiting illnesses and their families. It is expected that the need for palliative care will grow and it is considered important that health professionals and the New Zealanders they serve understand what it entails and how it can benefit patients and their families. New Zealand is the third best place in the world to die -just behind the United Kingdom and Australia, according to the Economist Intelligence Unit.[117] This is a reflection of the quality of care available for people at the end of life, and the cost and availability of that care.

Following an extensive consultation and analysis initiated in 1997, in 2001 the New Zealand Palliative Care Strategy set in place a systematic and informed approach to the provision and funding of palliative care services.[118]

The current New Zealand Government is concerned to ensure that all people who are dying, and their families, have access to palliative care services that are provided in a coordinated and culturally appropriate way. For this reason it has committed additional funding to ensure that this strategy can begin to be implemented immediately. The strategy recommends that palliative care should be generally available to people whose death from progressive disease is likely to occur within one year. An increasing number of New Zealanders are in need of palliative care services: the proportion of the population aged 65 or over is projected to more than double (from 12 per cent up to 26 per cent) over the next 50 years.

Government expenditure (GGE) in New Zealand is 40 per cent of GDP. Twenty per cent of GGE is spent on health. The New Zealand government supports 83 per cent of health care costs while households spend II per cent. Funding resources from the Ministry of Health are devolved to the District Health Boards (DHBs), which run and own public hospitals. Their objectives are to ensure accessible and appropriate services for people from lower socioeconomic groups; to establish accessible and appropriate services for Maiori and Pacific populations; and to ensure that the terminally ill and their families receive services when the former are discharged from hospital.

New Zealand has a mix of public and private hospitals, but public hospitals dominate hospital care, including virtually all emergency care.

The Government's vision in implementing the strategy is that all people who are terminally ill and could benefit from palliative care should have timely access to quality palliative care services that are culturally appropriate to the people they serve. Thus the government is committed to: ensuring that at least one local palliative care service is available for each DHB; developing specialist palliative care services; implementing hospital palliative care teams and ensuring their lifelong training; developing quality requirements for palliative care services; informing the public about palliative care services; and addressing issues of income support.

## Palliative care services and hospice care

It should be pointed out that in New Zealand the term 'hospice' has more than one meaning. It is used to refer to not only residential healthcare homes for the elderly at the end of their lives, but also to the concept and methods of palliative care for both inpatients and outpatients.

Palliative care is recognized nationwide as a legitimate component of healthcare and it is not delivered solely by hospices. It is also provided by GPs, district nurses, in residential care facilities and in hospitals. Over 700 doctors, nurses and healthcare professionals provide palliative care services in New Zealand, while 7,000 volunteers (out of a population of four million) deliver hospice services totalling 480,000 hours a year.

Palliative care in New Zealand arose within local communities in order to provide holistic care for adults with terminal cancer through the support of local funding and volunteers. The starting point for hospice care is the acceptance of the reality of death. Death is not an illness requiring treatment but the end of life's journey, which requires adequate pain relief, holistic care and compassionate assistance. Assuring quality care for the terminally ill and support for their families is considered essential for the future wellbeing of New Zealand society.

Palliative care is intended for people who are dying from active, progressive diseases or other conditions that are not responsive to curative treatment. Palliative care embraces the physical, social, emotional and spiritual elements of wellbeing and enhances a person's quality of life while they are dying. Palliative care services are generally provided by a multidisciplinary team that works with the dying person and provides support for their family. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It aims to provide relief from distressing symptoms, and integrates physical, social, emotional and spiritual aspects of care to help the dying and their family attain an acceptable quality of life. It offers help to the family carers during the person's illness and the family's bereavement.

There are a number of factors preventing delivery of the best palliative care, among them a lack of recognition that people affected by conditions other than cancer can benefit from palliative care services, a lack of workforce planning for palliative care, and variability in the funding of palliative care services.

Modern hospices in New Zealand can be traced back to the model of St Christopher's Hospice, inspired by the charisma and skill of Dame Cicely Saunders and her unique zeal in promoting the concept of hospice care internationally. Twelve years after the opening of St Christopher's Hospice in London, in June I979, New Zealand's first hospice, Mary Potter Hospice, was opened in Wellington. Later that year, Te Omanga Hospice opened in Lower Hutt, and St Joseph's Mercy Hospice in Auckland.[119] Increasingly, hospices have become associated as places where people die, but such a notion is impoverishing. In New Zealand today, a hospice is regarded primarily as the manifestation of a concept of care, or a philosophy of care. Initially, hospice programmes emphasized inpatient care of the terminally ill: patients were admitted to a residential facility where they received comfort and care from an attentive, multidisciplinary team of caregivers until they died. Hospice programmes now primarily provide a wide range of residential and homebased services, together with a day centre where patients who live at home are able to come to be assessed, receive counselling, advice, engage in activities and have companionship. From small beginnings the hospice movement in New Zealand has now developed into forty

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two hospice programmes. A key goal of the hospice movement is its educational role for the medical and nursing professions and wider community.

Hospice New Zealand is a national hospice body that promotes hospice and palliative care.[20] It is actively involved in research and education, workforce development, establishing standards of healthcare, providing information and advice to hospices, stakeholders and the general public, and helping and supporting hospices nationwide.

## Where care is provided

Currently New Zealand has four hospitalbased palliative care teams; these are located in Auckland, Waikato, Christchurch and Wellington. DHBs will set up hospital palliative care teams in locations where they are currently lacking.

Throughout the country, palliative care services are provided in inpatient centres and at patients' homes. They support the choice to die at home since research shows that 50-70 per cent of people would prefer home care. Information on services provided is available at the URLs of hospices located in each geographical area.[21]

Each of the hospices offers a number of palliative care services. For example, Amitabha Hospice Service at Forrest Hill, Auckland, provides hospice volunteer caregiver support in all suburbs of greater Auckland. Following the WHO guidelines for palliative care and the New Zealand Palliative Care Strategy, the Amitabha Hospice provides free practical help and companionship for those with progressive degenerative conditions or terminal illness through the aid of specially trained volunteers, thus improving the quality of life of patients and their families. By bringing compassionate care into the individual's home with multicultural and multilingual staff and volunteers, Amitabha caregivers offer people the option of remaining in their own homes. Services provided include pastoral care from qualified practitioners for people of all spiritual beliefs, and the provision of relaxation, meditation, massage, reiki and stress management treatments. Amitabha Hospice caregivers offer free assistance at home by giving practical help where appropriate, such as doing shopping, making light meals, giving massages and teaching relaxation and meditation techniques. They offer respite to the usual caregiver or family member, enabling the latter to have 'time out' to rest, work, do errands or simply take a break.

## Legal aspects

In New Zealand, the question of legalizing euthanasia and/or physicianassisted suicide (PAS) is an ongoing debate. Discussions about euthanasia often arise in the media in response to high profile court cases, whether national or foreign, or when there are visits to New Zealand by individuals promoting euthanasia or speaking against it.

In 2015, a lawyer who was suffering from a terminal brain cancer sought a High Court ruling to confirm that assisted dying was not unlawful under the Crimes Act, and that a ban on assisted dying contravened her human rights under the New Zealand Bill of Rights Act. The Court found that assisted dying was unlawful and that the relevant provisions of the Crimes Act were consistent with the rights and freedoms contained in the Bill of Rights Act. It further suggested that changes to the law could only be made by Parliament. Following this ruling, a petition organized by the Voluntary Euthanasia Society was presented to Parliament in June 2015. It asked that the House of Representatives investigate public attitudes towards the introduction of legislation permitting medically assisted dying.

Many people see this issue primarily as a debate about freedom of choice. The opponents to euthanasia consider that a change in the law would pose real dangers for New Zealand's society, and from the experience in other countries they fear that, in spite of lawmakers' best intentions, there would be no adequate legal safeguards to protect vulnerable groups such as children, the elderly, or those with disabilities should euthanasia or PAS be legalized.[122]

Hospice New Zealand does not support a change in the law to legalize assisted dying in any form. Nor does it consider that a change in the law would be in the best interests of the people they care for. The whole ethos of hospice and palliative care as defined by the WHO is that it 'intends neither to hasten nor postpone death'.

## Cost of palliative care

All of New Zealand's four million residents have access to a broad range of health and disability services with substantive government funding. The publicly funded system covers public health preventive and promotional services, inpatient and outpatient hospital care, primary health care services, inpatient and outpatient prescription drugs, mental healthcare, dental care for school children, and disability support services. Residents have free choice of a GP. Healthcare is mostly free for children under age six, and is subsidized to a significant degree for all people enrolled with Primary Health Organizations, which includes 95 per cent of the public.

Notforprofit insurers generally cover private medical care. Private insurance is most commonly used to cover costsharing requirements, elective surgery in private hospitals, and specialist outpatient consultations. About onethird of New Zealanders have some form of private health insurance.

Patients are billed copayments for pharmaceuticals, private hospital or specialist care, and adult dental care; copayments for GPs have been reduced markedly in recent years. Complementary and alternative medicines and therapies are paid for outofpocket. Such payments, including both cost sharing and expenditure paid directly by private households, accounted for I4 per cent of total national health expenditures in 2007.

The Government is committed to funding essential palliative care services and to ensure these are available. Healthcare public funding is derived from general taxation (85 per cent), levies on employers (7 per cent), and local government (8 per cent). Overall, public funding accounts for about 78 per cent of healthcare expenditure. However, palliative care in New Zealand is currently substantially underresourced. The Government provides on average just over 50 per cent of hospice core functions (some hospices receive only 38 per cent of their total budget while others receive up to 75 per cent). The remaining amount is funded by public donations.

The Government spends approximately $50 million a year on palliative care, while $22 million is raised through charitable donations to fund palliative care services.

Vai indietro all’Indice

# South Africa

## Background

The Republic of South Africa is a multiethnic society five times as large as the UK, encompassing among its fiftytwo million inhabitants a wide variety of cultures, languages, and religions. Its pluralistic makeup is reflected in its constitutional recognition of eleven official languages, including English, which is commonly used in public and commercial life and ranked fourth in the nation as a firstspoken language.

South Africa enjoys a relatively high GDP per capita compared to other countries in SubSaharan Africa ($II,750 at purchasing power parity for 20I2). Despite this, South Africa is still burdened by a relatively high rate of poverty and unemployment, and is also among the top ten countries of the world for its income inequality.

Life expectancy in 2009 was 7I years for a white and 48 years for a black South African. The healthcare spending in the country is about 9 per cent of GDP. About 20 per cent of South Africa's population uses private healthcare, with I5 per cent covered by medical insurance. The rest either pay outofpocket (OOP) or access the subsidized care provided by the public health sector. Data from the General Household Survey 20022007[I23] indicate that the racial distribution of medical scheme coverage is very skewed. While only .I5 per cent of the total population belongs to a medical scheme, the comparable figure is 66 per cent for the white population.[I24]

People choose to purchase certain healthcare services from the private sector even if they are not insured: out of the 85 per cent of citizens who do not have medical scheme coverage, 29 per cent used a private facility and incurred OOP expenditure on healthcare while only 20 per cent did not have any OOP costs. This seems to be a reflection of people's general dissatisfaction with the public sector. User satisfaction is lower for public health facilities than it is for private ones, and this gap appears to have widened in recent years. The Department of Health (DH) provides leadership and coordination of health services with a view to promoting the health of all people in South Africa through an accessible, caring and high quality health system based on a primary healthcare approach. This objective is not yet reached: South Africa ranks 30th among the 40 countries analyzed by the Economist Intelligent Unit in its 2010 Quality of Death survey.[125] DH is supposed to provide a framework for a structured uniform health system within South Africa. The department's goals over the medium term do not include palliative care among the strategic priorities, which feature making progress towards universal health coverage, preventing disease and promoting health, improving health facility planning by implementing norms and standards, improving financial management, developing an efficient health management information system for improved decisionmaking, improving the quality of care, and improving human resources for health by ensuring adequate training and accountability measures.

## Palliative care services and hospice care

Palliative care is an approach that improves the quality of life of patients and their families when faced with problems associated with lifethreatening illness. It promotes the prevention and relief of suffering by means of early identification, and the accurate assessment and treatment of pain and other physical, psychosocial and spiritual problems. Any person of any age who has a lifelimiting condition qualifies for palliative care, provided they consent to joining a hospice programme. Many different types of illnesses are included, the most common of which are cancer and AIDS.

Hospices and partner organizations in South Africa are supported by the Hospice Palliative Care Association of South Africa (HPCA), an organization that promotes quality in life, dignity in death and support in bereavement for everyone living with a lifethreatening illness.[126] The HPCA is also active in spreading the understanding that hospices are about life, living and love. This is meant to change perceptions about hospices so that people are not fearful of receiving hospice care when they or their family need it.

Hospices deliver palliative care in South Africa in three main ways:

- Hospice homebased care: mobile teams of professionally supervised trained community caregivers travel to people's homes and support and teach families to provide care at home. Not only is this cost effective but it also allows the patient to be at home, which is often where they prefer to remain.
- Hospice community centres: many hospices work from established bases within the community. At these bases they meet with groups of people who have palliative care needs. The type of patient who would attend these meetings is still reasonably well and mobile. Doctors, nurses, social workers and other professionals will attend the centres regularly to assist those with individual needs. These centres provide excellent forums where people facing lifelimiting illness can connect meaningfully with others in support groups. At many such centres, a variety of skills are also taught and incomegenerating projects initiated.
- Hospice inpatient units: some hospices have inpatient units. This is a facility that provides 24hour palliative care. Usually these units have a small number of beds and specific criteria for admission. A patient who has pain that is difficult to control at home, a patient whose family needs respite, or a patient who has absolutely no support systems at home are some of those who may be admitted to an inpatient unit.

Different hospices may have slightly varying admission criteria depending on their resources and limitations, such as geographical distance or staff availability. However, all hospices are committed to seeing that patients' palliative care needs are met. Anyone may refer a patient to a hospice: friends, neighbours, family members or the patients themselves. Hospice nurses will then visit patients to assess whether they are in need of palliative care. Patients may also be admitted if they have a direct referral from a healthcare professional (a doctor or nurse).

When a patient is accepted into a hospice programme, the hospice team together with the patient develop a tailormade plan of care. The main things a hospice can help with are pain and symptom control, psychosocial support and advice, spiritual and emotional support and bereavement support. The hospice may also help in equipping the patient's home with essential equipment, such as a bed, wheelchair or
commode.

Palliative care in South Africa does not address only the elderly: child mortality in South Africa is high, although under-five mortality declined between 2000 and 2011, from 74 to 47 per thousand live births. The decline was attributed to the provision of better services to communities. In 2012, only 2.7 per cent of HIV positive mothers transmitted the virus to their babies, a significant decrease from previous years.

'The majority of people have seen people dying since they were children', says Irish doctor Anne Merriman, Nobel Peace Prize winner and leader of Palliative Care in Africa, 'so they're much better at bereavement than we are'. Palliative Treatment for Children South Africa (PATCH) is an inclusive and compassionate network that aims to share specialized knowledge, to provide tools and opportunities to ensure the best possible care for children with lifethreatening and lifelimiting illnesses, and to offer support to families and lay caregivers. PATCH membership is composed of healthcare professionals, family members and community members with an interest in palliative care for children.

## Where care is provided

Unlike many Western countries, in South Africa death is not a taboo. Death, particularly since AIDS swept across the continent, is never far away. Africans also have strong community care networks through family and friends. 'If someone is living alone, the neighbours will come and help because they're part of the community', says Anne Merriman. This is reflected in the Quality of Death Index, in which South Africa scores highly when it comes to the availability of volunteer workers for endoflife care.[127]

Aside from hospice programmes, palliative care may also be delivered by trained specialists across the healthcare continuum. Some hospitals have palliative care teams or wards. Through HPCAdriven initiatives, many doctors, nurses, pastors and social workers from NGOs and the public and private healthcare sector are receiving training in and providing palliative care.

Hospices can be found throughout the country and their number is increasing. In 2011 there were 202 hospices compared with 52 hospices in 2004.

Location and information on hospices in each province can be found at the HPCA site.[128]

## Legal aspects

In the 1990s, the South African Law Commission conducted an exhaustive review of the state of the law with regard to endoflife, concluding that: 'At present, the position in our law is that the termination of a person's life is unlawful, even if the motive for such conduct is to end the person's unbearable suffering, even where the suffering person has expressed the wish to die or has even begged to be killed.'[129] Such as it is, the law relies on portions of cognate legislation and case law. The Commission reviewed a selection of cases of mercy killing that went to trial. The perpetrators were found guilty of murder but none served an actual jail sentence. Perhaps because of community sympathy, 'the courts sought to reflect the sense of justice of the community regarding the blameworthiness of the accused by imposing very light sentences'.[130]

The euthanasia debate in South Africa essentially concerns the balance between the constitutional guarantees of the right to life, and the rights to dignity and to autonomy. The right to life 'is not merely a right to biological life; it is a claim and entitlement to a particular quality of life', wrote Daniel J. Ncayiyana, adding:

> It does not follow that South Africa is a safe and appropriate place for liberalised voluntary euthanasia legislation. Euthanasia -a recourse of last resort -can only really be justified in a country with the very best medical care for all, a wellorganised and universally accessible palliative care and support system, stable and wellfunctioning (particularly judicial) institutions, and a strong culture of respect for human life. In South Africa, with its severe constraints on health care facilities and the totally inadequate allocation of resources for highly effective medical treatments, there is a real risk of euthanasia becoming a substitute for proper care for the terminally ill and other patients in dire medical straits.
>
> Even more damning for South Africa is the pervasive lack of an ethos of respect for human life. We are an extraordinarily violent society, with over 45 murders committed daily and interpersonal violence the second highest cause of death. Mob justice, police brutality and xenophobia abound. Needless deaths occur regularly in our hospitals through staff neglect and
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> indifference. Health care providers think nothing of downing tools and walking off, abandoning critically ill patients, or of blocking ambulances with critical emergencies from entering health facilities during labour disputes.
>
> In the circumstances, euthanasia cannot be at the top of the wishlist of things that must be accomplished in order to improve the human condition

of South Africans.[131]

Other relevant subjects involved in the legal debate are advance directives, terminal pain management and withholding and withdrawing potentially lifesustaining treatments.[132]

Advance directives involve an endoflife decisionmaking practice that recognizes the moral right of individuals to future control over their medical treatment in the eventuality that they may become incompetent to make their own endoflife decisions. Clear affirmation in statutory law with regard to the legal status of advance directives would assist in focusing people's minds on making decisions at the right time about possible future scenarios in which they would not want to find themselves helpless to decide. There are two main classes of advance directives:

1. A 'living will' is an instruction directive by which a competent person instructs others to withhold or withdraw potentially lifesustaining treatment should they become incapable of refusing such treatment themselves.
2. A 'power of attorney for healthcare' is a substitute directive by which a competent person appoints or mandates a specific person as their proxy healthcare decisionmaker should they become incompetent to make their own healthcare decisions.

Appropriate and adequate terminal pain management that provides comfort and care to a patient suffering from a terminal disease and whose death is imminent may have the secondary effect of hastening death. Potentially, this exposes medical practitioners to criminal and civil liability. Consequently, there is a need for legislative clarity that ensures adequate terminal pain management according to the standard of medical care appropriate in the circumstances. This could be ensured by an honest application of the doctrine of double effect: legitimizing the possible shortening of life if that is the foreseen but unintended outcome of appropriately managing terminal pain and suffering.

Withholding and withdrawing potentially lifesustaining treatment is an endoflife decisionmaking practice that recognizes the moral right to a natural death of individuals in the terminal phase of dying, as well as the corresponding moral obligation of caregivers, family and state to respect that right. The law should be clear about the legal status of this right and obligation. The law should recognize and create the space for ethically responsible decisionmaking with regard to withholding or withdrawing potentially lifesustaining treatment from competent and incompetent persons.

## Cost of palliative care

In South Africa, hospice palliative care is given freely, regardless of a person's ability to pay.[133] South African hospices rely on funding support from government, corporations and communities. Volunteers are also essential to the work in local hospices. The South African government is moving fast to integrate palliative care into the health systems, but it is still limited by resources. This calls for creative ways of diversifying the funding.

Palliative care funding should be seen as a very useful investment for governments. The palliative care approach has contributed not only to reducing suffering among patients with cancer, AIDS and other conditions, but also programmes using the palliative care approach have demonstrated their cost effectiveness and reduced unnecessary patient admissions. In addition, AIDS programmes using the palliative care approach have contributed significantly to prevention of further HIV transmission through accessing other family members, and to tracking, testing and treating children and adults living with HIV.

The Abundant Life programme established at Victoria Hospital in Cape Town and adapted for the South African setting from the UK Gold Standards Framework, has proved successful in assisting patients with organ failure, and in reducing the number of hospital admissions for this group of patients. A report on this programme also demonstrated savings for patients and for hospitals.[134]

The palliative care fraternity in South Africa has received assistance from traditional palliative care donors such as the US government through PEPPFAR, the UK Government through DFID, and the EU through International Cooperation and Development, as well as from trusts, foundations and other funding institutions and individuals. These entities have provided direct funding, twinning programmes and training opportunities for staff.

However, as a result of the 2009 worldwide economic crisis, donor funding has been seriously reduced, and hospices in South Africa are being forced to reduce staff and cut back on the numbers of patients they care for.

Vai indietro all’Indice

# Note a Prassi e legislazione sul fine vita in Paesi contrassegnati con #

1. http://www.who.int/cancer/media/ FINALPalliative%20Care%20Module.pdf [Accessed l8 July 20l5J.

2. David Clark, 'International progress in creating palliative medicine as a specialised discipline', in Geoffrey Hanks (Ed.) Oxford Textbook of Palliative Medicine, Oxford University Press, 20ll.

3. Sheila Payne and Tom Lynch, 'International progress in creating palliative medicine as a specialized discipline and the development of palliative care', in Nathan Cherny et al. (Ed.'s) Oxford Textbook of Palliative Medicine (5th ed.) Oxford: Oxford University Press, 20l5.

4. M.R. Rajagopal and Reena George, 'Providing palliative care in economically disadvantaged countries', in Nathan Cherny et al. (Ed.'s) Oxford Textbook of Palliative Medicine (5th ed.), cit.

5. The quality of death: ranking endoflife care across the world. Economist Intelligence Unit, London; 20l0. www.qualityofdeath.org [Accessed 2 June 20l5J.

6. John J Bonica, The Management of Pain: With Special Emphasis on the Use of Analgesic Block in Diagnosis)Prognosis and Therapy (London: Henry Kimpton, l953).

7. The first hospices were opened over a century ago in Dublin (Our Lady's Hospice, l879) and in the East End of London (St Joseph's Hospice, Hackney, l905) by Catholic nuns as a charitable and religious mission caring for those dying of tuberculosis and living in poverty. Considerably later, St Christopher's Hospice opened in South London in l967.

8. Mary Baines, 'From pioneer days to implementation: lessons to be learnt', European Journal of Palliative Care, l8, 5 (20ll).

9. Thomas J. Smith and J. Brian Cassel, 'The economic challenges of palliative medicine', in Nathan Cherny et al. (Ed.'s), Oxford Textbook of Palliative Medicine, cit.

l0. Ethics Task Force of the European Association for Palliative Care, 'Euthanasia and physicianassisted suicide: a view from an EAPC Ethics Task Force', Palliative Medicine, 2003.

ll. Nonvoluntary euthanasia is defined as an act conducted where the consent of the patient is unavailable. Involuntary euthanasia is defined as an act conducted against the will of the patient. Passive euthanasia is defined as an act that entails the withholding of treatment.

l2. In The Netherlands, the penal code was changed, whereas in Belgium and Luxembourg it was not, and thus in these latter countries euthanasia remains voluntary premeditated homicide, punishable by penal law, and nonpunishable solely under the conditions specified by the law.

l3. See details in the section on the US at page l59.

l4. An overview (current as of 3 September, 20l5) of the current status of legislation and legislative proposals in each US state is presented by the Death with Dignity National Center at http://www.deathwithdignity.org/ advocates/national [Accessed 20 September 20l5J.

l5. See details in the section on Canada at page l65.

l6. See details in the section on Australia at page l77.

l7. There is one exception in the Northern Territory, Australia, as described in a following section, on page l78.

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l8. J. Pereira, 'Legalizing euthanasia or assisted suicide: the illusion of safe guards and controls', Current Oncology, l8, 2: (April 20ll), pp. 38-45.

l9. The quality of death, Economist Intelligence Unit, cit.

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Amitabha Hospice Service Forrest Hill, Auckland /243/ Arohanui Hospice Service Palmerston North /244/ Ashburton Palliative Care Ashburton /245/ Community Hospice

Service Whakatane /247/ Cranford Hospice Hastings /248/ Hibiscus Coast Hospice Whangaparaoa /250/ Hospice Bay of Islands Kerikeri /252/ Hospice New Zealand Wellington /2l0/ Hospice Wanganui Wanganui /253/ Kaipara Palliative Care Society Dargaville /254/

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