Diwedd Oes Gwell 2024

# Amser i ofalu yng Nghymru

Goblygiadau i Gymru yn sgil 'Amser i ofalu: Canfyddiadau arolwg cynrychiolaeth genedlaethol o brofiadau diwedd oes yng Nghymru a Lloegr

**Briff polisi**

**Awst 2024**

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# Cyd-destun

Maenifer y bobl y mae angen gofal lliniarol a diwedd oes arnynt yng Nghymru'n cynyddu. Wrth i'n poblogaeth heneiddio, mae mwy o bobl yn byw'n hirach, yn aml gyda chyflyrau cymhleth lluosog. Yn 2019, amcangyfrifwyd bod angen gofal lliniarol ar 30,000 o bobl yng Nghymru [1]. Erbyn 2022, roedd hyn wedi codi i dros 32,000. Os bydd y tueddiadau presennol yn parhau, bydd tua 37,000 o bobl yn marw gydag anghenion gofal lliniarol bob blwyddyn erbyn y 2040au.

Mae'r gwasanaeth iechyd yn wynebu pwysau ariannol eithafol. Gyda lefelau sylweddol o gostau gofal iechyd yn codi yn ystod blwyddyn olaf oes, mae gan ddulliau cynllunio a darparu gofal diwedd oes oblygiadau enfawr i'r GIG ac i wariant cyhoeddus yn ehangach. Mae sicrhau bod gofal lliniarol a gofal diwedd oes yn diwallu anghenion pobl yn effeithiol ac yn effeithlon yn elfen hanfodol o wasanaeth iechyd a gofal cymdeithasol cynaliadwy. Gan fod marw, marwolaeth a phrofedigaeth yn effeithio ar bob un ohonom, mae hi er budd pawb i ni gael hyn yn iawn.

Ym mis Hydref 2022, amlinellodd Llywodraeth Cymru ei gweledigaeth ar gyfer gofal lliniarol a diwedd oes mewn Datganiad Ansawdd [2]. Mae hyn yn disgrifio'r hyn y mae angen i wasanaethau ei ddarparu er mwyn i ofal fod yn ddiogel, yn amserol, yn effeithiol, i ganolbwyntio ar yr unigolyn a bod yn effeithlon ac yn deg. Yn anffodus, mae'r dyfyniadau a'r data yn y briffio hwn yn dangos bod ffordd bell i fynd cyn i hyn ddod yn realiti i bawb. Mae gormod o bobl yn marw mewn poen, heb y gofal a'r gefnogaeth mae eu hangen arnyn nhw a'u teuluoedd.

Mae'r papur briffio hwn yn crynhoi canfyddiadau arolwg a anfonwyd at sampl gynrychioliadol genedlaethol o 1,500 o bobl yng Nghymru a oedd wedi cofrestru marwolaeth rhwng Awst a Rhagfyr 2022. Cafwyd 557 o ymatebion, sy'n golygu mai dyma'r arolwg cenedlaethol ôl-brofedigaeth mwyaf erioed i gael ei gynnal yng Nghymru.

Cynhyrchwyd yr ymchwil y mae'r briff hwn yn seiliedig arni trwy'r rhaglen Diwedd Oes Gwell, sef cydweithrediad rhwng Marie Curie, Sefydliad Cicely Saunders Coleg y Brenin Llundain, Ysgol Feddygaeth Hull York, Prifysgol Hull, a Phrifysgol Caergrawnt. Adroddiad ymchwil Diwedd Oes Gwell, Amser i Ofalu: Gellir darllen canfyddiadau arolwg cynrychiolaeth genedlaethol o brofiadau diwedd oes yng Nghymru a Lloegr yma: mariecurie.org.uk/better-end-life-report

# Canfyddiadau allweddol

## Mae gormod o bobl yn marw mewn poen a heb y cymorth mae ei angen arnynt ar gyfer eu symptomau

- Cafwyd effaith ddifrifol neu lethol ar fwy nag un o bob tri o bobl oherwydd poen (36%) neu ddiffyg anadl (40%) yn ystod wythnos olaf eu bywyd, ac roedd llawer yn teimlo'n bryderus ac yn isel.
- Roedd un o bob naw (11%) o bobl a fu farw yn yr ysbyty wedi bod yno lai na 24 awr.
- Roedd trafferthion wrth gael meddyginiaethau yn gyffredin, yn enwedig 'y tu allan i oriau'.
- Mae anghydraddoldebau o ran mynediad at ofal lliniarol yn parhau, yn enwedig i bobl hŷn a'r rhai sydd â diagnosis nad yw'n ganser.

## Mae bylchau mewn gofal cymunedol 24/7 yn atal pobl rhag marw mewn cysur gartref

- Mae'r rhan fwyaf o ofal diwedd oes yn digwydd yn y gymuned: Treuliodd 60% o bobl y rhan fwyaf o'u tri mis olaf mewn cartref preifat ac roedd 22% mewn cartref gofal yn bennaf, ac roedd 13% wedi treulio'r rhan fwyaf o'u tri mis olaf yn yr ysbyty.
- Roedd y defnydd o ofal brys yn uchel, gyda bron i hanner y bobl fu farw yn defnyddio ambiwlans (48%) neu'n ymweld ag adrannau damweiniau ac achosion brys (45%) yn ystod eu tri mis olaf.
- Roedd 94% o ymatebwyr yr arolwg yr oedd aelod o'u teulu wedi marw gartref yn teimlo mai dyma'r lle iawn, o'u cymharu â 73% o'r rhai y bu farw'r aelod o'u teulu mewn cartref gofal a 66% o'r rhai y bu farw'r aelod o'u teulu yn yr ysbyty. Nid oedd gan bron i hanner (46%) y bobl a fu farw yn yr ysbyty unrhyw ffrindiau na theulu'n bresennol.

## Mae cleifion a theuluoedd yn dioddef pan fydd gwasanaethau'n cael eu cydlynu'n wael, ac nid oes gan weithwyr proffesiynol amser

- Roedd bron i hanner (47%) ohonynt yn anhapus gydag o leiaf un agwedd ar y gofal a gafodd aelod o'u teulu. Gwnaeth un o bob 15 gŵyn ffurfiol.
- Yn aml, nid oedd gan staff ar draws lleoliadau iechyd a gofal cymdeithasol ddigon o amser i ddarparu gofal digonol i bobl a oedd yn marw.
- Roedd un o bob pedwar (25%) o bobl a fu farw naill ai'n debygol neu yn bendant ddim yn gwybod y gallent farw oherwydd eu salwch.
- Dywedodd mwy nag un o bob tri (37%) o'r ymatebwyr nad oedd gweithwyr gofal iechyd proffesiynol wedi trafod marwolaeth a marw gyda'r person a fu farw, tra bod un o bob pedwar (25%) yn ansicr.

## Mae gofalwyr di-dâl yn ymgymryd â rolau rhoi gofal sylweddol heb fawr o gefnogaeth

- Roedd y rhan fwyaf o'r ymatebwyr yn ymgymryd â rolau rhoi gofal hanfodol, ond roedd llawer yn teimlo nad oedd ganddynt yr wybodaeth, y sgiliau na'r mynediad at gymorth proffesiynol mae eu hangen.

- O'r ymatebwyr sy'n dal i fod mewn gwaith, cymerodd 14% rhwng 31 a 90 diwrnod o absenoldeb â thâl neu'n ddi-dâl, wrth i 6% roi'r gorau i'w swyddi neu newid swyddi (gan gynnwys ymddeol yn gynnar), i ofalu am eu hanwyliaid.

- Roedd un o bob chwech (16%) o'r ymatebwyr yn bodloni'r meini prawf ar gyfer 'galar aflonyddedig' – gyda phobl mewn profedigaeth a oedd yn iau, yn fenyw, neu'n briod i'r person a fu farw, yn ogystal â'r rhai a oedd â phrofiad gwael o ofal, sydd fwyaf agored i niwed.

- Nid oedd bron i bedwar o bob pump (79%) o'r rhai â galar aflonyddedig wedi derbyn unrhyw gymorth gan wasanaethau profedigaeth.

# 1 Mae gormod o bobl yn marw mewn poen a heb y cymorth mae ei angen arnynt ar gyfer eu symptomau

Bod yn rhydd o boen a symptomau eraill yw prif flaenoriaeth y rhan fwyaf o bobl ar gyfer dyddiau olaf eu bywydau [3]. Er y bydd llawer o bobl â salwch angheuol yn profi poen, gyda'r driniaeth, y gofal a'r gefnogaeth gywir, dylai fod yn bosibl rheoli hyn fel ei fod yn fwy hylaw.

Mae canfyddiadau'r arolwg yn dangos bod poen wedi cael effaith ddifrifol neu lethol ar fwy nag un o bob tri (36%) o bobl a fu farw yn ystod eu hwythnos olaf o fywyd, a bod diffyg anadl yn effeithio'n ddifrifol neu'n llethol ar hyd yn oed mwy (40%) arnynt. Roedd symptomau seicolegol hefyd yn gyffredin iawn yn ystod yr wythnos olaf o fywyd: Roedd gorbryder yn cael effaith ar 36% o bobl y rhan fwyaf o'r amser neu drwy'r amser, ac roedd 34% yn teimlo'n isel y rhan fwyaf o'r amser. Er nad yw'r canfyddiadau'n dweud wrthym a wnaeth symptomau'n cael eu datrys neu eu gwella, maent yn nodi bylchau yn y ddarpariaeth gofal bresennol.

Roedd symptomau difrifol a llethol yn fwy tebygol o effeithio ar bobl a fu farw yn yr ysbyty yn hytrach nag yn y cartref neu mewn cartref gofal. Gall hyn adlewyrchu'r ffaith bod pobl sydd â symptomau mwy trallodus yn fwy tebygol o gael eu derbyn i'r ysbyty. Roedd un o bob naw (11%) o bobl a fu farw yn yr ysbyty wedi bod yno llai na 24 awr, gan awgrymu mynediad heb ei gynllunio neu mewn argyfwng.

## Mynediad at feddyginiaethau ar gyfer poen a symptomau eraill

Mae meddyginiaethau yn hanfodol bwysig i reoli poen a symptomau eraill ar ddiwedd oes. Roedd ymatebion yr arolwg yn adlewyrchu'r dystiolaeth bresennol am anawsterau wrth gael gafael ar feddyginiaethau, yn enwedig dros nos ac ar benwythnosau [4].

> **"Gwrthododd [y] meddyg teulu y tu allan i oriau ddod allan [a] dywedodd wrtha i i ffonio['r] parafeddygon [...] sy'n golygu na chafodd fy ngŵr unrhyw feddyginiaeth poen neu orbryder drwy gydol y nos. Roedd hyn yn ofnadwy i'w weld ac yn gwbl annerbyniol.**
>
> Bu farw o sawl cyflwr

Ni fydd pob fferyllfa gymunedol yn stocio meddyginiaethau diwedd oes, sy'n gallu creu problemau ychwanegol i bobl mewn ardaloedd gwledig neu heb fynediad at gar.

> **"Yn ystod yr wythnos olaf, cafodd gyrrwr chwistrell ei osod. Nid oedd gan [y] fferyllfa leol bob amser stoc o['r] meddyginiaethau a gallai amseroedd agor [y] fferyllfa dros y penwythnos fod yn broblem. Golygodd y ddau bwynt hyn fy mod i'n gorfod teithio 20 milltir i gasglu presgripsiynau a meddyginiaethau, a oedd yn tynnu amser gwerthfawr i mi gyda fy ngŵr. Hefyd, achosodd straen ychwanegol gorfod dod o hyd i rywun i eistedd gydag ef. Roedd fy ngŵr yn bryderus iawn am y sefyllfa hon.**
>
> Bu farw o sawl cyflwr

Mae Cymru wedi arwain y ffordd o ran datblygu gwasanaethau arloesol i gefnogi gwell mynediad at feddyginiaethau, megis cyflwyno meddyginiaethau 'Rhag Ofn' i gerbydau brys ar draws Gwasanaeth Ambiwlans Cymru [5], a chyflwyno pecyn cymorth i ofalwyr roi meddyginiaethau di-nodwydd ar gyfer symptomau sydyn cyffredin yn y cartref [6]. Fodd bynnag, nid yw pawb a allai elwa o'r cynlluniau hyn yn gallu cael mynediad atynt.

Mae'r cynllun rhagnodi rhagfynegol 'Rhag Ofn' yn caniatáu i feddygon teulu ragnodi cyffuriau o restr gymeradwy i bobl sydd â diagnosis terfynol sydd â phrognosis o dri mis neu lai. Yna gellir cadw'r rhain yn ddiogel yng nghartref yr unigolyn i'w gweinyddu pan fydd angen, felly nid oes bylchau o ran rheoli symptomau [7]. Er bod y cynllun wedi bod ar waith yng Nghymru ers dros ddegawd, mae tystiolaeth anecdotaidd yn awgrymu bod gwahaniaethau rhanbarthol o ran sut mae'n cael ei weithredu. Mae'n hanfodol bod pawb sy'n agosáu at ddiwedd ei oes a allai elwa o gefnogaeth y cynlluniau hyn yn cael mynediad atynt, yn unol â chanllawiau NICE [8].

## Mynediad at ofal lliniarol

Mae gofal lliniarol yn atal ac yn lleddfu dioddefaint trwy nodi'n gynnar, ac asesu a thrin poen a phroblemau eraill yn gywir, p'un a yw'n gorfforol, yn seicogymdeithasol neu'n ysbrydol. Mae meddygon teulu, nyrsys ardal a chymunedol a gweithwyr gofal iechyd proffesiynol eraill yn chwarae rôl bwysig wrth ddarparu gofal lliniarol, ac mae arbenigwyr gofal lliniarol wedi'u hyfforddi i ofalu am y rhai sydd â symptomau neu bryderon mwy cymhleth.

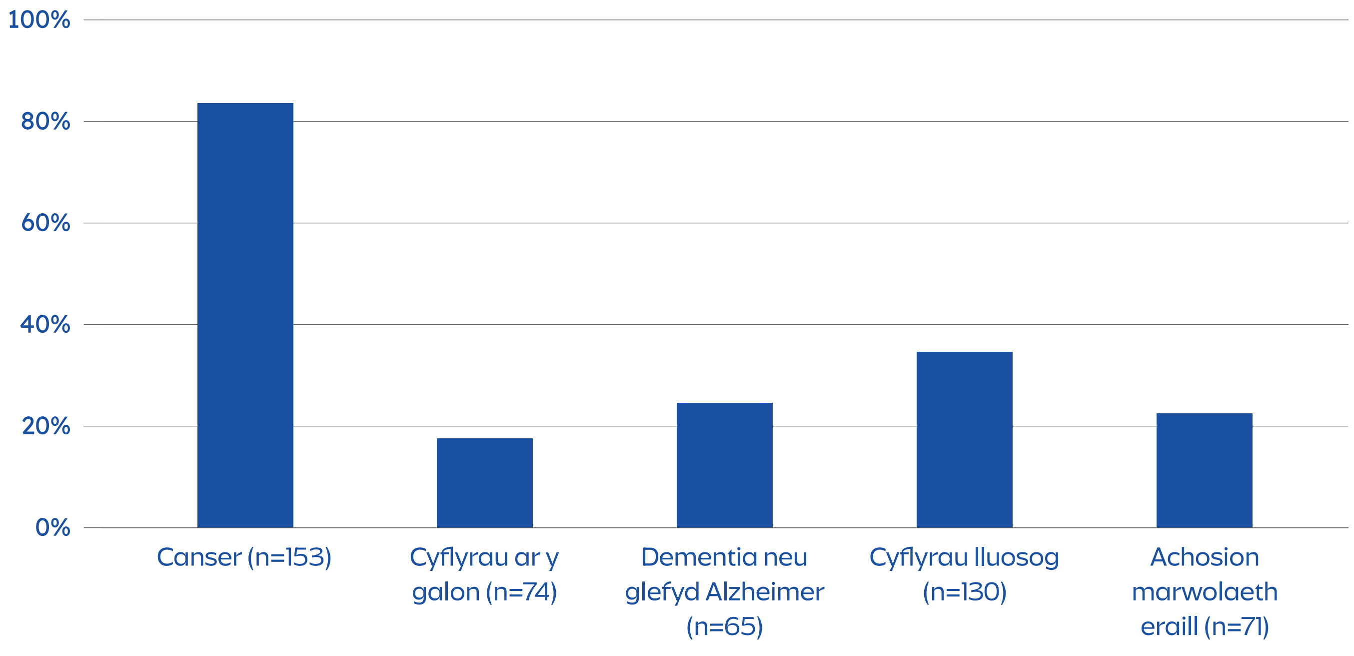
Er bod adborth yr arolwg am y gefnogaeth gan dimau gofal lliniarol yn gadarnhaol ar y cyfan, roedd tystiolaeth gref o anghydraddoldebau mynediad yn y canfyddiadau [9].

> **"Roedd y gofal a ddarparwyd gan y tîm gofal lliniarol cymunedol yn eithriadol [...] Pe bai unrhyw faterion yr oedd angen mynd i'r afael â nhw, byddent yn cysylltu â'r nyrs gymunedol, a fyddai wedyn yn cysylltu â'r meddyg teulu pe bai angen.**
>
> Bu farw o ganser

> **"Ni chynigiwyd unrhyw gefnogaeth gan y tîm gofal lliniarol. Pe bai cynnig, byddem wedi ei chroesawu. Efallai y byddai gwybodaeth am ofal fy ngwraig wedi bod yn gliriach. Roedd yn teimlo fel brwydr gyson yn lle hynny. Ni ddylai wedi bod fel hyn.**
>
> Bu farw o gyflwr y galon

Pobl 85 oed neu hŷn a'r rhai a fu farw o gyflyrau heblaw canser oedd leiaf tebygol o dderbyn gofal lliniarol arbenigol, er gwaethaf tystiolaeth bod baich y symptomau'n debyg ar draws gwahanol gyflyrau. Mae angen gweithredu ar lefel polisi cenedlaethol a darpariaeth gwasanaethau lleol i gyflawni'r ymrwymiad yn natganiad ansawdd Llywodraeth Cymru ar gyfer Gofal Lliniarol a Gofal Diwedd Oes Llywodraeth Cymru i leihau anghydraddoldebau mynediad a ddangosir.

**Derbyn gofal gan arbenigwyr gofal lliniarol (mewn unrhyw leoliad) yng Nghymru yn ystod tri mis olaf bywyd ar draws y pum achos marwolaeth mwyaf cyffredin**



**(Ffynhonnell: Johansson et al., 2024, t. 99)**

# 2 Mae bylchau mewn gofal cymunedol 24/7 yn atal pobl rhag marw mewn cysur gartref

Mae canfyddiadau'r arolwg yn dangos bod y rhan fwyaf o ofal diwedd oes yn digwydd yn y gymuned. Yn ystod tri mis olaf eu bywydau, treuliodd 60% o'r bobl a fu farw y rhan fwyaf o'u hamser mewn cartref preifat ac roedd 22% mewn cartref gofal yn bennaf, ac roedd un o bob wyth (13%) wedi treulio'r rhan fwyaf o'u hamser yn yr ysbyty. Mae meddygon teulu, nyrsys ardal a chymunedol, a chynorthwywyr gofal iechyd yn chwarae rôl hanfodol wrth ofalu am bobl ar ddiwedd eu hoes yn y gymuned. Fodd bynnag, nid oedd bron i un o bob pump (19%) o bobl a fu farw wedi cael unrhyw gyswllt â meddyg teulu naill ai'n bersonol neu dros y ffôn yn ystod eu tri mis olaf. Adroddwyd yn eang am anawsterau wrth gael mynediad at wasanaethau meddygon teulu.

> **"[Roedden ni'n] cael trafferth cael mynediad at y meddyg teulu, gan nad oedd derbynyddion o gymorth i hwyluso hyn. Roedd cynllun osgoi ysbyty ar waith ond roedd yn ddibynnol ar gael mynediad at feddyg teulu.**
>
> Bu farw o sawl cyflwr

Roedd y defnydd o ofal brys yn uchel, gyda bron i hanner y bobl fu farw'n defnyddio ambiwlans (48%) neu'n ymweld ag adran damweiniau ac achosion brys (45%) yn ystod eu tri mis olaf. Roedd nifer wedi profi amseroedd aros hir i ambiwlansys gyrraedd, neu wedi treulio oriau yn aros i gael eu gweld mewn adrannau damweiniau ac achosion brys.

> **“[...] Galwodd meddyg i'w weld gartref. [...] Galwodd hi ambiwlans [a] dywedodd ei fod yn hynod o frys. Arhoson ni fwy nag 8 awr. Cafodd ei gludo i'r ysbyty am 7pm, bu'n gorwedd yn yr ambiwlans tan 7.30am y bore canlynol.**
>
> Bu farw o gyflwr ysgyfaint

Mae gwasanaethau gofal cymunedol hygyrch ac effeithiol yn cefnogi lles cleifion a gofalwyr a gallant helpu i atal derbyniadau i'r ysbyty y gellir eu hosgoi ar ddiwedd hoes [10]. Mae mentrau fel Safonau Daffodil wedi'u datblygu i gefnogi ymarfer cyffredinol a fferyllfeydd cymunedol i ddarparu gwell gofal diwedd oes yn y gymuned [11]. Eto i gyd, mae anawsterau wrth gyrchu gwasanaethau, meddyginiaeth, offer a chefnogaeth gan weithwyr proffesiynol yn parhau, gyda phroblemau'n arbennig o amlwg yn ystod y cyfnod 'y tu allan i oriau'.

Mae Llywodraeth Cymru wedi ymrwymo i wella gofal cymunedol drwy ei rhaglen Ymhellach, yn Gyflymach, gyda chyllid ychwanegol i Fyrddau Iechyd i gynyddu capasiti nyrsys ardal a nyrsys clinigol cymunedol arbenigol i ddarparu gofal diwedd oes [12]. Mae angen asesiad o ran a yw hyn wedi'i gyflawni, gyda dysgu yn cael ei rannu a neilltuo cyllid rheolaidd i gefnogi capasiti gofal lliniarol cymunedol a gofal diwedd oes wedi'u gwarantu i'r dyfodol.

## Cwrdd â blaenoriaethau pobl ar gyfer lle gofal a man y farwolaeth

Er bod llawer o bobl yn dweud eu bod yn dymuno cael gofal a marw gartref, mae hanner yr holl farwolaethau yng Nghymru yn digwydd yn yr ysbyty [13]. Mae lle gofal a marwolaeth yn fater cymhleth; ni ddylid ystyried marw gartref ynddo'i hun yn ddirprwy ar gyfer profiad diwedd oes da. Gall ffactorau lluosog effeithio ar hyn, gan gynnwys argaeledd gwasanaethau iechyd a gofal cymunedol, gallu teulu a ffrindiau i ddiwallu anghenion yr unigolyn, a'r amodau y tu mewn i'r cartref.

Roedd bron pob un (94%) o ymatebwyr yr oedd aelod o'u teulu wedi marw gartref yn teimlo mai dyna oedd y lle iawn, o'u cymharu ag 85% o'r rhai y bu farw yr aelod o'u teulu mewn hosbis, 73% o'r rhai y bu farw yr aelod o'u teulu mewn cartref gofal a 66% o'r rhai y bu farw yr aelod o'u teulu yn yr ysbyty. Mae hyn yn adlewyrchu y gall dewisiadau newid wrth i anghenion ddatblygu ac i rai, efallai na fydd y cartref yn opsiwn priodol neu hyfyw mwyach. Gall hyn beri gofid i ofalwyr teulu.

> **"Fe wnes i addo i fy nhad y gallai farw gartref ond oherwydd y diffyg cefnogaeth roedd yn rhaid i mi dorri'r addewid. Doeddwn i ddim yn gallu darparu'r gofal yr oedd ei angen arno.**
>
> Bu farw o ganser

Nododd yr arolwg enghreifftiau o brofiadau diwedd oes cadarnhaol mewn ysbytai, a hwylusir yn aml gan ymddygiad staff.

> **"Roedd yr ysbyty lle bu farw, y nyrsys a'r meddygon yn anhygoel. Roedden nhw'n rhoi'r wybodaeth ddiweddaraf i ni, yn gwneud yn siŵr ei fod yn gyfforddus. Pe byddem yn meddwl ar unrhyw adeg ei fod mewn poen, byddent yn ei asesu i dawelu ein meddyliau.**
>
> Bu farw o gyflwr ysgyfaint

I eraill, nid oedd yr ysbyty yn darparu'r amgylchedd priodol i'w hanwyliaid, ac nid oedd gan bron i hanner (46%) y bobl a fu farw yn yr ysbyty unrhyw ffrindiau na theulu'n bresennol.

> **"Dwi'n teimlo bod mam wedi dioddef anurddas wrth i'w marwolaeth nesáu. Roedd y dyddiau olaf yn amhersonol. Amgylchynwyd ei gwely gan len bapur las, doedd dim preifatrwydd, dim urddas. Bu'n rhaid i mi erfyn ar staff i'w symud i ystafell ochr, a gwnaethon nhw hynny yn y diwedd bum awr cyn iddi farw.**
>
> Bu farw o gyflwr ysgyfaint

Mae galluogi pobl i farw gartref os mai dyma yw eu dewis yn egwyddor graidd o bolisi gofal diwedd oes ac mae ganddo'r potensial i leihau'r pwysau ar wasanaethau gofal brys ac argyfwng yn sylweddol. Er mwyn i hyn ddigwydd, rhaid comisiynu gwasanaethau cymunedol i ddiwallu anghenion pobl, 24 awr y dydd. Gall partneriaethau rhwng darparwyr statudol a'r trydydd sector gynyddu capasiti cymunedol a sicrhau canlyniadau cadarnhaol i gleifion a'u teuluoedd, ond nid yw'r gwasanaethau hyn ar gael ledled Cymru gyfan i bawb mae eu hangen arnynt.

## Astudiaeth Achos:
## Gweithio mewn partneriaeth i ymateb yn gyflym i anghenion cleifion yn y gymuned

Mae gwasanaeth Hosbis Gartref Brys Marie Curie ym Mwrdd Iechyd Prifysgol Betsi Cadwaladr yn cael ei arwain gan nyrsys cofrestredig a'i gefnogi gan gynorthwywyr gofal iechyd sy'n darparu gofal nyrsio lliniarol ac ymatebol a diwedd oes hyblyg, ar fyr rybudd i gleifion gartref. Mae'r gwasanaeth dros nos hwn ar gael rhwng 10pm a 7am, gan weithio mewn partneriaeth â'r gwasanaeth meddygon teulu y tu allan i oriau a gwasanaeth Nyrsio Ardal dros nos. Mae'r gwasanaethau hyn yn cynnwys yr holl gleifion gofal lliniarol sy'n byw mewn lleoliad daearyddol y cytunwyd arno. Yn 2023/24, cefnogodd y gwasanaeth 600 o gleifion, a galluogi mwy na 95% i farw yn eu lle marw dewisol (o gleifion lle'r oedd yr wybodaeth hon yn hysbys).

# 3 Mae cleifion a theuluoedd yn dioddef pan fydd gwasanaethau'n cael eu cydlynu'n wael, ac mae gweithwyr proffesiynol yn brin o amser

Dywedodd bron i hanner (47%) yr holl ymatebwyr eu bod yn anhapus ag un agwedd neu fwy ar y gofal a gafodd aelod o'u teulu, a gwnaeth un o bob 15 gŵyn ffurfiol. Roedd materion a arweiniodd at gwynion yn cynnwys gofal gwael neu dim gofal neu arosiadau hir, anghytundeb ynghylch gadael yr ysbyty neu asesiadau, a methu cyfathrebu neu rannu gwybodaeth.

> **"Doedd neb yn gwybod pwy oedd yn gwneud beth ac roedden ni fel teulu yn cael trafferth gwybod y llwybrau cywir a phwy i gysylltu â nhw. Roedd pobl yn disgwyl ein bod ni'n gwybod [...] Fe wnaethon ni dreulio oriau ac oriau yn cael ein trosglwyddo i bobl eraill er mwyn dod o hyd i'r person/adran iawn i helpu. Doedd neb yn cyfathrebu â'i gilydd.**
>
> Bu farw o gyflwr arall

Gyda llawer o weithwyr proffesiynol a gwasanaethau gwahanol yn gysylltiedig, roedd yn peri trallod ac yn llethol i gleifion a'u gofalwyr pan oedd gofal yn cael ei gydlynu'n wael. Roedd cyfrifoldebau gofalu a gweinyddol sylweddol yn disgyn i deulu a ffrindiau, a oedd yn aml yn teimlo nad oeddent wedi'u paratoi at gyfer hynny nac yn cael eu cefnogi. Dywedodd llai na hanner (43%) o ymatebwyr yr arolwg bod ganddynt berson cyswllt allweddol i gydlynu eu gofal.

> **"[Roeddwn i] yn teimlo fy mod i'n cael fy ngadael ar fy mhen fy hun. Roedd yr holl gyfrifoldeb dros i fwyd, meddyginiaeth, apwyntiadau, gofal, ymgysylltu â llawer o wahanol bobl a gwasanaethau i gyd yn cwympo arna i. Doedd dim un pwynt cyswllt – roedd llawer o wahanol bobl yn neidio i mewn ac allan eto, ond doedd dim un person a oedd yn cydlynu'r cymorth.**
>
> Bu farw o ganser

Mae hyn yn tanlinellu pwysigrwydd cyflawni'r bwriad yn y Datganiad Ansawdd ar gyfer Gofal Lliniarol a Gofal Diwedd Oes ar gyfer un pwynt mynediad 24/7 i ofal cydgysylltiedig, meddyginiaeth a chyngor am ofal diwedd oes. Mae angen cynllun gweithredu a llinell amser ar gyfer cyflawni dyheadau'r Datganiad Ansawdd ym mhob Bwrdd Iechyd ar frys. Dylid archwilio modelau gwasanaeth mwy integredig ac arloesol o ofal a chydweithio ar draws y system hefyd, gan ddysgu o enghreifftiau o arfer da sy'n lleihau derbyniadau i'r ysbyty ac yn sicrhau gwell canlyniadau i gleifion, fel model REACT yn Bradford [14].

## Dim amser i ofalu

Dywedodd ymatebwyr yr arolwg nad oedd gan staff ar draws lleoliadau iechyd a gofal cymdeithasol ddigon o amser i ddarparu gofal i bobl sy'n marw, neu nad oedd cymorth ar gael cyhyd neu mor aml ag y bo angen.

> **"Roedd y gofal lliniarol a'r nyrsys ardal a'r meddyg teulu yn wych, ond dim ond ychydig o weithiau'r wythnos daethon nhw am hanner awr.**
>
> Bu farw o ganser

> **"Er bod gennym feddyg teulu rhagorol, nid oedd bob amser yn hawdd cael gafael arno ac roedd hyn yn rhwystredig iawn ar adegau.**
>
> Bu farw o ddementia neu glefyd Alzheimer

Mae tystiolaeth amlwg o'r pwysau ar y gweithlu ar draws iechyd a gofal cymdeithasol. Mae meddygon teulu, nyrsys a chynorthwywyr gofal iechyd yn darparu'r rhan fwyaf o ofal lliniarol, yn aml ochr yn ochr ag ystod o wasanaethau eraill. Er bod nifer y bobl y mae angen gofal lliniarol a diwedd oes arnynt wedi cynyddu'n sylweddol yng Nghymru yn ystod y blynyddoedd diwethaf, gostyngodd nifer y meddygon teulu llawn amser dros 21% rhwng 2013 a 2022 [15]. Cynyddodd swyddi gwag nyrsio gan 58% rhwng 2021 a 2022 [16]. Rhaid i gynllunio gweithlu'r dyfodol ystyried y cynnydd sylweddol yn yr angen am ragolwg o ofal lliniarol ar gyfer y degawdau nesaf.

## Sgyrsiau am ofal diwedd oes yn digwydd yn rhy hwyr

Dylai pawb yng Nghymru sydd ag anghenion gofal lliniarol gael eu cefnogi i gymryd rhan mewn Cynllunio Gofal Ymlaen Llaw a Gofal yn y Dyfodol (AFCP), gan roi'r cyfle iddynt drafod eu hanghenion, eu dymuniadau a'u dewisiadau ar gyfer gofal ar ddiwedd oes. Dylai'r dewisiadau hyn gael eu cofnodi a'u hadolygu'n rheolaidd. Eto i gyd, roedd un o bob pedwar (25%) o bobl a fu farw naill ai'n debygol neu yn bendant ddim yn gwybod y gallent farw oherwydd eu salwch, yn ôl aelodau o'u teulu. Dywedodd mwy nag un o bob tri (36%) o'r ymatebwyr eu bod ond wedi dod yn ymwybodol bod eu hanwyliaid yn marw ym mis olaf eu bywyd.

Er na fydd pawb eisiau neu'n gallu cael sgyrsiau am eu dymuniadau diwedd oes, dylid cynnig y cyfle i bawb. Dywedodd mwy nag un o bob tri (37%) o'r ymatebwyr nad oedd gweithwyr gofal iechyd proffesiynol wedi trafod marwolaeth a marw gyda'r person a fu farw, ac roedd un o bob pedwar (25%) ohonynt yn ansicr. Er bod y sgyrsiau hyn yn fwy tebygol o fod wedi digwydd rhwng gweithwyr gofal iechyd proffesiynol a theulu'r person (66%), dywedodd rhai fod gweithwyr gofal iechyd proffesiynol wedi delio â hyn yn wael.

> **"Roedd un meddyg [ysbyty] yn hynod lym a doedd dim llawer o empathi ganddo pan [glywson] ni fod fy nhad yn sâl tu hwnt a mwy na thebyg yng nghamau olaf ei fywyd.**
>
> Bu farw o strôc

Mae'n hanfodol bod gan weithwyr iechyd a gofal proffesiynol yr amser a'r sgiliau mae eu hangen i hwyluso AFCP. Gall systemau cydlynu gofal electronig gefnogi AFCP trwy gynnwys anghenion a dewisiadau mewn cofnodion gofal, y gellir eu rhannu ymhlith pawb sy'n ymwneud â gofal unigolyn gyda'u caniatâd.

# 4 Mae Gofalwyr di-dâl yn ymgymryd â rolau rhoi gofal sylweddol heb fawr o gefnogaeth

Mae gofalwyr di-dâl – sy'n tueddu i fod yn deulu ac yn ffrindiau – yn chwarae rôl hanfodol mewn gofal diwedd oes, ond yn aml nid yw eu hanghenion nhw'n cael eu cydnabod na'u cefnogi'n briodol. Roedd y rhan fwyaf o ymatebwyr yr arolwg wedi bod yn ymwneud â gofalu am y person a fu farw: Fe wnaeth 54% eu helpu i fynd i apwyntiadau neu driniaeth, roedd 56% yn helpu gyda thriniaeth feddygol, a 76% yn treulio amser 'ar alw' (h.y. bod modd cysylltu â nhw os oedd angen), fel arfer am fwy na 50 awr yr wythnos. Dywedodd llawer o'r ymatebwyr eu bod yn teimlo nad oedd ganddynt yr wybodaeth na'r sgiliau ond nad oeddent yn gallu cael gafael ar gefnogaeth ddigonol, gyda chyfathrebu gwael gan weithwyr proffesiynol a chydlynu gofal yn achos straen sylweddol.

> **"Roedd hi'n anodd oherwydd yn aml, doedden ni ddim yn siŵr os oedden ni'n gwneud y peth iawn. Cawson drafferth yn ei chodi, ei throi, ei chadw'n lân a mynd â hi i'r toiled. Dyna pam roedden ni'n ysu am ofalwyr i ddod i'n helpu – ond roedd prinder gofalwyr. Felly, dalion ni ati, ar ein pennau ein hunain, i wneud ein gorau glas.**
>
> Bu farw o ganser

Mewn llawer o achosion, roedd gofalwyr eu hunain yn fregus neu mewn iechyd gwael, yn enwedig lle cafodd y person a fu farw ddiagnosis o ddementia.

> **"[Dylai fod] mwy o gydnabyddiaeth a chefnogaeth i aelodau o'r teulu sy'n gwneud y gofalu - fy mam yn yr achos yma, roedd hi'n teimlo'n ynysig ac yn isel ei hysbryd oherwydd dim ond am gyfnodau byr o amser gallai adael fy nhad.**
>
> Bu farw o ddementia neu glefyd Alzheimer

## Astudiaeth Achos:
## Cefnogi pobl â dementia cyfnod hwyr a'u gofalwyr yng Nghymru

Lansiwyd Gwasanaeth Gofal a Seibiannau Dementia Marie Curie yn Abertawe a Chastell-nedd Port Talbot ym mis Hydref 2022 gyda chyllid gan Fwrdd Partneriaeth Ranbarthol Gorllewin Morgannwg. Mae'r gwasanaeth yn cefnogi'r nifer cynyddol o bobl yn yr ardal sy'n byw gyda dementia cyfnod hwyr, gan eu galluogi i aros gartref trwy ddarparu gofal o ansawdd uchel ochr yn ochr â chymorth rhagweithiol i ofalwyr.

Mae'r gwasanaeth yn cynnwys dwy elfen gysylltiedig, mewn haenau yn ôl lefel angen y claf. Mae'r Gwasanaeth Cyfaill Dementia, sydd wedi'i staffio gan wirfoddolwyr hyfforddedig, yn darparu cymorth emosiynol, cymorth ymarferol a seibiant am hyd at dair awr yr wythnos i bobl â lefelau is o angen a'u gofalwyr. Mae'r Gwasanaeth Gofal Seibiant Dementia, wedi'i staffio gan Nyrs Gofrestredig a Chynorthwywyr Gofal Iechyd, yn darparu asesiadau i bobl ag anghenion mwy cymhleth, cymorth gyda gweithgareddau dyddiol, cefnogaeth emosiynol a seibiant. Gall pobl symud rhwng lefelau gwasanaeth wrth i'w hanghenion newid. Mae'r integreiddio hwn yn sicrhau bod adnoddau'n cael eu defnyddio'n effeithlon trwy ddarparu'r lefel fwyaf priodol o gymorth.

Mae'r gwasanaeth wedi cael derbyniad da, ac mae tystiolaeth anecdotaidd yn awgrymu ei fod wedi atal anghenion cynyddol o ofal ac atgyfeirio at ysbytai a chartrefi gofal, gan ganiatáu darparu gofal gartref yn unol â dewisiadau pobl.

Wrth ragweld y bydd nifer y bobl hŷn sy'n byw gyda dementia yng Nghymru yn cynnyddu gan 70% rhwng 2019 a 2040, bydd cefnogi pobl â dementia a'u gofalwyr yn dod yn rhan gynyddol bwysig o ofal diwedd oes.

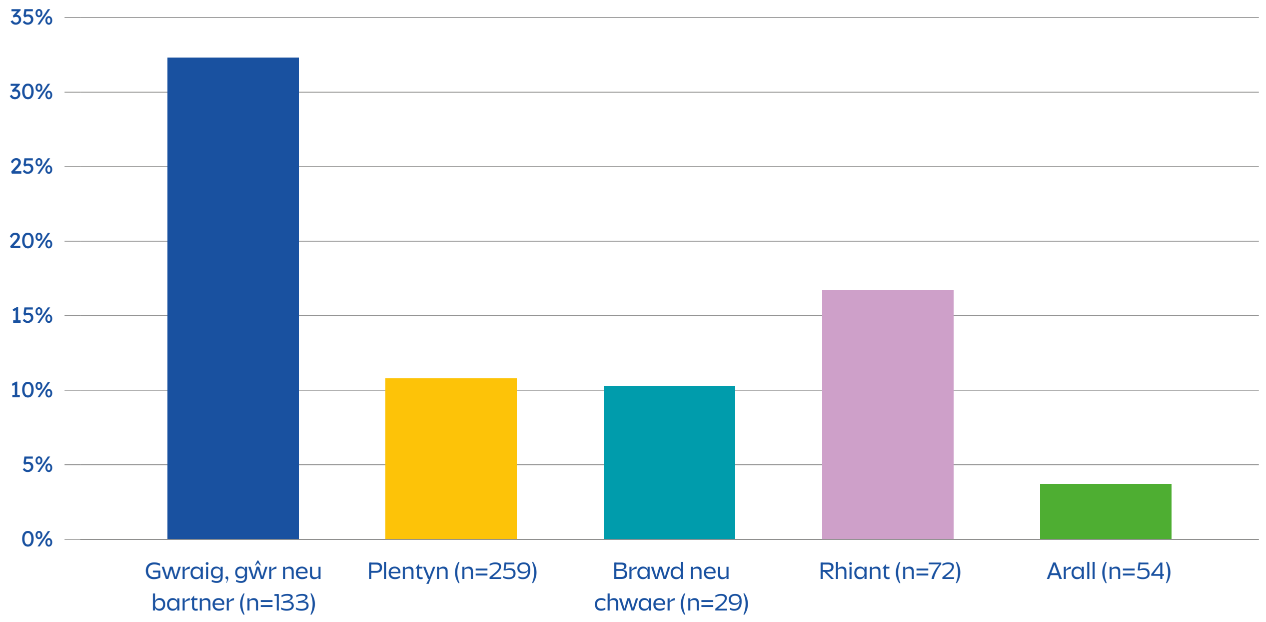
Yn ogystal â bod yn anodd yn emosiynol ac yn gorfforol, gall gofalu am berthynas ar ddiwedd oes hefyd gael effaith ariannol a phroffesiynol. O'r ymatebwyr hynny sy'n dal i fod mewn gwaith, cymerodd 14% rhwng 31 a 90 diwrnod o absenoldeb â thâl neu'n ddi-dâl, a gwnaeth 6% roi'r gorau i'w swydd neu newid swyddi (gan gynnwys ymddeol yn gynnar) i ofalu am eu hanwyliaid. Dywedodd eraill eu bod wedi cwtogi cyflogau wrth iddynt leihau eu horiau i ddarparu gofal.

> **"Dwi dal yn y niwl ar ôl ei cholli. Dw i wedi lleihau fy oriau yn y gwaith, dw i wedi newid, mae bywyd wedi newid.**
>
> Galar anaflonyddedig

## Nid yw pobl sydd â galar aflonyddedig yn cael eu cefnogi'n ddigonol

I rai pobl, gall profedigaeth arwain at alar aflonyddedig: ymateb galar gwanychol sy'n achosi trallod seiciatrig. Roedd un o bob chwech (16%) o ymatebwyr yr arolwg yn bodloni'r meini prawf ar gyfer galar aflonyddedig, gyda chyfraddau uwch ymhlith ymatebwyr iau, ymatebwyr benywaidd, a'r rhai a oedd yn briod i'r person a fu farw.

**Nifer yr achosion o alar aflonyddedig ymhlith ymatebwyr yng Nghymru yn ôl eu perthynas â'r person a fu farw**



**(Ffynhonnell: Johansson et al., 2024, t. 110)**

Roedd gan ymatebwyr a oedd yn anhapus ag agweddau ar ofal neu a oedd yn teimlo nad oedd gweithwyr gofal iechyd proffesiynol wedi gwrando arnynt nac wedi cyfathrebu'n dda lefelau uwch o alar aflonyddedig.

> **“Dw i wedi ystyried gwneud cwyn sawl tro ond mae'r galar wedi bod mor llethol, dw i wedi gorfod dechrau dod i dderbyn popeth sydd wedi digwydd. Nid yw'r boen a'r euogrwydd byth yn fy ngadael.**
>
> Galar aflonyddedig

Nid oedd bron i bedwar o bob pump (79%) o'r rhai a oedd yn bodloni'r meini prawf ar gyfer galar aflonyddedig wedi gallu cyrchu cymorth profedigaeth, gan awgrymu angen sylweddol nad yw'n cael ei ddiwallu.

# 5 Gwneud profiad diwedd oes da yn bosibl i bawb

Mae llawer o'r dyfyniadau a chanfyddiadau o'r ymchwil yn ddeunydd darllen sy'n cynhyrfu ac sydd weithiau'n frawychus. Fodd bynnag, roedd yna hefyd nifer o enghreifftiau o brofiadau gofal diwedd oes cadarnhaol.

> **"Roedd Mam a minnau'n ffodus i gael profiad cadarnhaol gan rai o'r bobl mwyaf anhygoel dwi erioed wedi cwrdd â nhw. Daeth y bobl hyn (staff) i fod fel teulu wrth i mi ymweld bron bob dydd am 6 blynedd.**
>
> Bu farw o ddementia neu glefyd Alzheimer

> **"Roedd y tîm gofal yn yr ysbyty lle bu farw yn anhygoel. Canmoliaeth i'r doctoriaid a'r nyrsys. Roedden nhw esbonio popeth cam wrth gam ac yn rhoi gwybod i ni'n rheolaidd beth oedd yn digwydd gydag e.**
>
> Bu farw o gyflwr ysgyfaint

Yng Nghymru, mae'r Datganiad Ansawdd ar gyfer Gofal Lliniarol a Gofal Diwedd Oes eisoes wedi disgrifio'r gefnogaeth y dylai pawb y mae angen gofal lliniarol a gofal diwedd oes arnynt ei derbyn. Rydym yn gwybod beth yw gofal diwedd oes da, ond nid oes cynllun clir eto ar gyfer sut y bydd y Datganiad Ansawdd yn cael ei weithredu. Dylai mynd i'r afael â'r bwlch gweithredu hwn fod yn flaenoriaeth frys i Lywodraeth Cymru a'r Byrddau Iechyd.

# Argymhellion polisi

| | Argymhelliad | I’w roi ar waith gan |
|---|---|---|
| **Gwneud profiad diwedd oes da yn bosibl i bawb** | Mae'n rhaid datblygu cynllun gweithredu a fframwaith monitro sy'n nodi sut y bydd dyheadau'r Datganiad Ansawdd a'r fanyleb gwasanaeth sydd ar ddod yn cael eu cyflawni ym mhob Bwrdd Iechyd. | • Llywodraeth Cymru |
| **Gwell cefnogaeth i boen a symptomau eraill** | Dylid adolygu trefniadau lleol ar gyfer rhagnodi gofal diwedd oes, gan gynnwys comisiynu a defnyddio pecynnau Rhag Ofn, i nodi a mynd i'r afael â bylchau ac annhegwch o ran mynediad. | • Byrddau Iechyd |
| | Dylid comisiynu gwasanaethau fferylliaeth gymunedol i ddarparu set safonol o feddyginiaethau gofal lliniarol a sicrhau eu bod ar gael yn gyson 24/7. | • Byrddau Iechyd |
| | Dylid gwreiddio gofal lliniarol a gofal diwedd oes ar draws yr holl raglenni strategol perthnasol, rhwydweithiau clinigol, a Datganiadau Ansawdd sy'n benodol i gyflwr. | • Llywodraeth Cymru |
| **Darparu gofal cymunedol 24/7** | Rhaid cyflwyno mentrau i gynyddu capasiti gofal cymunedol, a dysgu drwy roi mentr ‘Ymhellach, yn Gyflymach’ ar waith a mentrau eraill a rennir, a neilltuo cyllid rheolaidd i gefnogi capasiti gofal lliniarol cymunedol a gofal diwedd oes wedi’u gwarantu ar gyfer y dyfodol. | • Llywodraeth Cymru<br>• Byrddau Iechyd<br>• Byrddau Partneriaeth Ranbarthol |
| | Dylid datblygu a chyflwyno proses gyfannol sy'n seiliedig ar ddata i asesu anghenion poblogaeth a phrofiadau o ofal lliniarol a diwedd oes ledled Cymru, gan alluogi dull mwy cydlynus o gomisiynu sy'n cynnwys partneriaid statudol a thrydydd sector. | • Llywodraeth Cymru<br>• Gweithrediaeth y GIG<br>• Iechyd a Gofal Digidol Cymru |

| | | |
|---|---|---|
| **Gwasanaethau integredig a gofal amserol a chydgysylltiedig** | Dylai systemau cydlynu gofal electronig weithio mewn ffordd sy'n annog eu defnydd parhaus a lle gellir rhannu'r cynnydd ar y defnydd ac argaeledd cofnodion a rennir, gan gynnwys cynllunio gofal ymlaen llaw, a'u harchwilio'n rheolaidd. | • Llywodraeth Cymru<br>• Gweithrediaeth y GIG<br>• Iechyd a Gofal Digidol Cymru |
| | Dylid cyhoeddi cynllun gweithlu gofal lliniarol a diwedd oes yn seiliedig ar amcanestyniadau wedi'u gwirio'n annibynnol o'r galw presennol ac yn y dyfodol. | • Llywodraeth Cymru<br>• Gweithrediaeth y GIG |
| | Dylai pob gweithiwr iechyd a gofal proffesiynol gael ei ariannu i dderbyn hyfforddiant a chael amser i ddilyn canllawiau cenedlaethol clir ar gynllunio gofal ymlaen llaw ac yn y dyfodol. | • AaGIC<br>• Gofal Cymdeithasol Cymru |
| **Cefnogaeth i ofalwyr di-dâl** | Dylid cyflwyno modelau ar gyfer darparu addysg i ofalwyr diwedd oes, gan ddysgu o enghreifftiau o arfer da fel hyfforddiant Cymorth Olaf yn yr Alban. | • Llywodraeth Cymru<br>• Byrddau Iechyd<br>• Awdurdodau Lleol |
| | Dylid datblygu a mabwysiadu pro-fforma o wybodaeth gofal iechyd allweddol sy'n ofynnol gan ofalwyr fel rhan o ofal arferol i bawb sydd â salwch datblygedig, ac fel rhan o'r cymorth sydd ar gael i bawb sy'n gofalu am rywun sydd â salwch angheuol. | • Byrddau Iechyd<br>• Awdurdodau Lleol |
| | Dylid treialu'r Adnodd Asesu Anghenion Cymorth i Ofalwyr (CSNAT) fel rhan o'r pecyn gofal i bobl ar ddiwedd eu hoes, er mwyn gwella asesiad a chymorth anghenion gofalwr. | • Gweithrediaeth y GIG<br>• Byrddau Iechyd<br>• Gofal Sylfaenol<br>• Awdurdodau Lleol |

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Better End of Life 2024

# Time to care in Wales

## Implications for Wales of ‘Time to care: Findings from a nationally representative survey of experiences at the end of life in England and Wales’

**Policy briefing**

Marie Curie

**August 2024**

# Context

The number of people who need palliative and end of life care in Wales is growing. As our population ages, more people are living longer, often with multiple complex conditions. In 2019, an estimated 30,000 people in Wales needed palliative care [1]. By 2022 this had risen to more than 32,000. If current trends continue approximately 37,000 people will die with palliative care needs each year by the 2040s.

The health service is facing extreme financial pressures. With significant levels of healthcare costs occurring within the last year of life, the design and delivery of end of life care has huge implications for the NHS and for public spending more widely. Ensuring palliative and end of life care meet people's needs effectively and efficiently is a vital component of a sustainable health and social care service. As dying, death and bereavement affect us all, it is in everyone's interest we get this right.

In October 2022, the Welsh Government set out its vision for palliative and end of life care in a Quality Statement [2]. This describes what services need to deliver for care to be safe, timely, effective, person-centred, efficient, and equitable. Unfortunately, the quotes and data in this briefing show there is a long way to go before this becomes a reality for all. Too many people are dying in pain, without the care and support they and their families need.

This briefing summarises findings from a survey that was sent to a nationally representative sample of 1,500 people in Wales who had registered a death between August and December 2022. There were 557 responses, making this the largest national post-bereavement survey ever to take place in Wales.

The research this briefing is based on was produced through the Better End of Life programme, a collaboration between Marie Curie, King's College London Cicely Saunders Institute, Hull York Medical School, the University of Hull, and the University of Cambridge. The full Better End of Life research report, Time to Care: Findings from a nationally representative survey of experiences at the end of life in England and Wales, can be read here: mariecurie.org.uk/better-end-life-report

# Key findings

## Too many people die in pain and without the support they need for their symptoms

- More than one in three people were severely or overwhelmingly affected by pain (36%) or breathlessness (40%) in their final week of life, and many felt anxious and depressed.
- One in nine (11%) people who died in hospital had been there less than 24 hours.
- Difficulties accessing medicines were common, particularly ‘out of hours’.
- Inequalities in access to palliative care persist, particularly for older people and those with a non-cancer diagnosis.

## Gaps in 24/7 community care prevent people from dying in comfort at home

- Most end of life care happens in the community: 60% of people spent most of their last three months of life in a private home and 22% were mostly in a care home, while 13% spent most of their last three months in hospital.
- Emergency care use was high, with almost half of people who died using an ambulance (48%) or visiting A&E (45%) in their final three months.
- 94% of survey respondents whose family member died at home felt this was the right place, compared to 73% of those whose family member died in a care home and 66% of those whose family member died in hospital. Almost half (46%) of people who died in hospital had no friends or family present.

## Patients and families suffer when services are poorly coordinated, and professionals lack time

- Almost half (47%) were unhappy with at least one aspect of the care their family member received. One in 15 made a formal complaint.
- Staff across health and social care settings often did not have enough time to provide adequate care for dying people.
- One in four (25%) people who died either probably or definitely did not know they might die because of their illness.
- More than one in three (37%) respondents said healthcare professionals had not discussed death and dying with the person who died, while one in four (25%) were unsure.

## Unpaid carers take on significant caregiving roles with little support

- Most respondents undertook essential caregiving roles, but many felt they lacked the knowledge, skills, and access to professional support needed.

- Of respondents still in work, 14% took between 31 and 90 days paid or unpaid leave, while 6% quit or changed their jobs (including retiring early), to care for their loved one.

- One in six (16%) respondents met the criteria for ‘disturbed grief’ – with bereaved people who were younger, female, or the spouse of the person who died, as well as those who had a poor experience of care, most at risk.

- Nearly four in five (79%) of those with disturbed grief had received no support from bereavement services.

# 1 Too many people die in pain and without the support they need for their symptoms

Being free of pain and other symptoms is most people's top priority for their final days of life [3]. While many people with a terminal illness will experience pain, with the right treatment, care, and support, it should be possible to get this under control so that it is more manageable.

The survey findings show that more than one in three (36%) people who died were severely or overwhelmingly affected by pain in their final week of life, and even more (40%) were severely or overwhelmingly affected by breathlessness. Psychological symptoms were also very common in the last week of life: 36% of people were affected by anxiety most or all of the time, and 34% felt depressed most of all of the time. Though the findings do not tell us whether symptoms resolved or improved, they indicate gaps in current care provision.

People who died in hospital rather than at home or in a care home were more likely to be affected by severe and overwhelming symptoms. This may reflect that people with more distressing symptoms are more likely to be admitted to hospital. One in nine (11%) people who died in hospital had been there less than 24 hours, suggesting an unplanned or emergency admission.

## Access to medicines for pain and other symptoms

Medicines are vitally important to the management of pain and other symptoms at the end of life. Survey responses reflected existing evidence about difficulties accessing medicines, particularly overnight and at weekends [4].

> **"[The] out-of-hours GP refused to come out [and] told me to phone [the] paramedics […] resulting in my husband not receiving pain or anxiety medication throughout the night. This was horrendous to watch and totally unacceptable.**
>
> Died from multiple conditions

Not every community pharmacy will stock end of life medicines, which can create additional problems for people in rural areas or without access to a car.

> **"In the last week, a syringe driver was set up. [The] local pharmacy didn't always have stock of [the] medications [and] weekend opening times of [the] pharmacy could be problematic. These two points resulted in me having to travel 20 miles to pick up prescriptions and medications, which deprived me of precious time with my husband. Plus, [it] caused added stress [of] having to find someone to sit with him. My husband was very anxious with this situation.**
>
> Died from multiple conditions

Wales has led the way in developing service innovations to support better access to medicines, such as the rollout of 'Just in Case' medicines to emergency vehicles across the Welsh Ambulance Service [5], and the introduction of a package of support for carers to administer needle-less medications for common breakthrough symptoms at home [6]. However, not everyone who could benefit from these schemes is able to access them.

The 'Just in Case' anticipatory prescribing scheme allows GPs to prescribe drugs from an approved list to people with a terminal diagnosis who have a prognosis of three months or less. These can then be kept safely in the person's home to be administered when required, so there are no gaps in symptom control [7]. Though the scheme has been in place in Wales for more than a decade, anecdotal evidence suggests that there are regional disparities in its implementation. It is essential that everyone approaching the end of life who could benefit from the support of these schemes has access, in accordance with NICE guidance [8].

## Access to palliative care

Palliative care prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial, or spiritual. GPs, district and community nurses and other healthcare professionals play an important role in the delivery of palliative care, while palliative care specialists are trained to care for those with more complex symptoms or concerns.

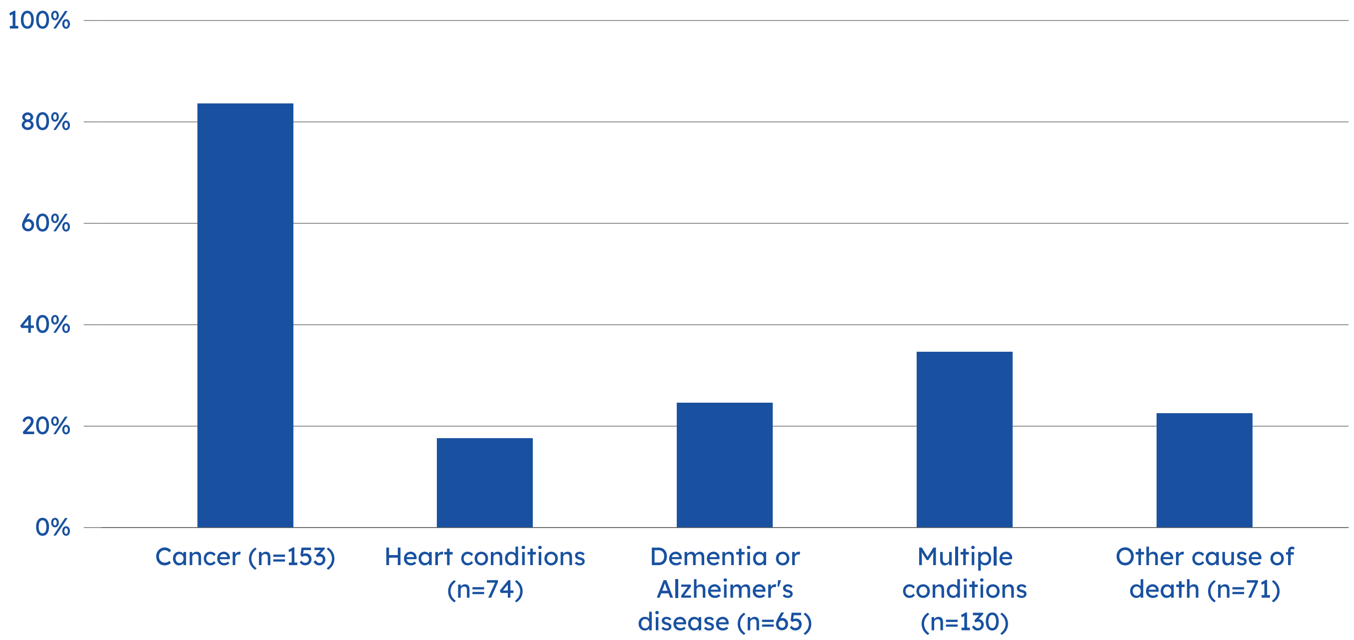
Though survey feedback about the support from palliative care teams was generally very positive, well-evidenced inequalities in access were reflected in the findings [9].

> **"Care provided by the community palliative care team was exceptional […] Any issues that needed addressing, they would contact the community nurse, who would then contact [the] GP if needed.**
>
> Died from cancer

> **"No support [was] offered from the palliative care team. If so, we would have welcomed it. Perhaps information about my wife's care would have been clearer. It felt like a constant battle instead. [It] shouldn't be like this.**
>
> Died from a heart condition

People aged 85 or over and those who died from conditions other than cancer were least likely to receive specialist palliative care, despite evidence that symptom burden is similar across different conditions. Action is needed at both a national policy and local service delivery level to deliver on the commitment in

**Receipt of care from palliative care specialists (in any setting) in Wales during the last three months of life across the five most common causes of death**



**(Source: Johansson et al., 2024, p. 99)**

# 2 Gaps in 24/7 community care prevent people from dying in comfort at home

The survey findings show that the majority of end of life care happens in the community. In the last three months of life, 60% of people who died spent most of their time in a private home and 22% were mostly in a care home, while one in eight (13%) spent most of their time in hospital. GPs, district and community nurses, and healthcare assistants play a critical role in caring for people at the end of life in the community. However, almost one in five (19%) people that died had no contact with a GP either in person or over the phone in their final three months. Difficulties accessing GP services were widely reported.

> **"[We had] difficulty accessing the GP, as receptionists were not helpful in facilitating this. A hospital avoidance plan was in place but was dependent on accessing a GP.**
>
> Died from multiple conditions

Emergency care use was high, with almost half of people who died using an ambulance (48%) or visiting an A&E department (45%) in their final three months. Many experienced long waits for ambulances to arrive, or spent hours waiting to be seen in A&E.

> **"[...] a doctor called to see him at home. [...] She called an ambulance [and] said it was extremely urgent, we waited over 8 hours. He was taken to hospital at 7pm, he lay in the ambulance until 7.30am the following morning.**
>
> Died from a lung condition

Accessible and effectively resourced community care services support the wellbeing of patients and carers and can help to prevent avoidable hospital admissions at the end of life [10]. Initiatives such as the Daffodil Standards have been developed to support general practice and community pharmacies in delivering better community end of life care [11]. Yet difficulties accessing services, medication, equipment, and support from professionals persist, with problems particularly pronounced during the 'out of hours' period.

The Welsh Government has committed to improve community care through its Further Faster programme, with additional funding to Health Boards to increase the capacity of district nursing and community clinical nurse specialists to provide end of life care [12]. An assessment is needed of whether this has delivered, with learnings shared and recurrent ringfenced funding to support community palliative and end of life care capacity guaranteed into the future.

## Meeting people's priorities for place of care and place of death

Though many people say they wish to be cared for and to die at home, half of all deaths in Wales take place in hospital [13]. Place of care and death is a complex issue; dying at home should not in itself be considered a proxy for a good end of life experience. Multiple factors can affect this, including the availability of community health and care services, the ability of family and friends to meet the person's needs, and the conditions inside the home.

Nearly all (94%) survey respondents whose family member died at home felt this was the right place, compared to 85% of those whose family member died in a hospice, 73% of those whose family member died in a care home and 66% of those whose family member died in hospital. This reflects that preferences may change as needs develop and for some, home may no longer be an appropriate or viable option. This can be distressing for family carers.

> **"I promised my dad he could die at home but due to the lack of support I had to break the promise. I was unable to provide the care he needed.**
>
> Died from cancer

The survey identified examples of positive end of life experiences in hospitals, often facilitated by the behaviour of staff.

> **"The hospital where he died, the nurses and doctors were amazing. They kept us up to date, made sure he was comfortable. If at any time we thought he was in pain, they would check him over to put us as ease.**
>
> Died from a lung condition

For others, hospital did not provide the appropriate environment for their loved one, and almost half (46%) of people who died in hospital had no friends or family present.

> **"I feel that my mum suffered an indignity leading up to her death. The final days were impersonal. Her bed was surrounded by a blue paper curtain, no privacy, no dignity. I had to plead with staff to move her to a side room, which they eventually did five hours before she died.**
>
> Died from a lung condition

Enabling people to die at home if this is their preference is a core tenet of end of life care policy and has the potential to significantly reduce pressures on urgent and emergency care services. For this to happen, community services must be commissioned to meet people's needs, 24 hours a day. Partnerships between statutory and third sector providers can increase community capacity and deliver positive outcomes for patients and their families, but these services are not available across the whole of Wales for everyone who needs them.

## Case Study:
## **Working in partnership to rapidly respond to patient needs in the community**

Marie Curie's Urgent Hospice at Home service in Betsi Cadwaladr University Health Board is led by registered nurses and supported by healthcare assistants providing flexible and responsive palliative and end of life nursing care, at short notice to patients at home. This overnight service runs from 10pm to 7am, working in partnership with the out of hours GP service and overnight District Nursing service. These services cover all palliative care patients who live in an agreed geographical location. In 2023/24, the service supported 600 patients, and enabled more than 95% to die in their preferred place of death (of patients where this information was known).

# 3 Patients and families suffer when services are poorly coordinated, and professionals lack time

Nearly half (47%) of all respondents reported that they were unhappy with one or more aspects of the care their family member received, and one in 15 made a formal complaint. Issues that led to complaints included poor or absent care or long waits, disagreement with discharges or assessments, and communication or information sharing failures.

> **"No one knew who was doing what and us as a family struggled to know the correct routes and who to contact. We were just expected to know […] We spent plenty of hours being passed about in order to find the right person/department to help. No one communicated with each other.**
>
> Died from other condition

With many different professionals and services involved, it was distressing and overwhelming for patients and their carers when care was poorly coordinated. Significant caring and administrative responsibilities fell to family and friends, who often felt unprepared and unsupported. Fewer than half (43%) of survey respondents said they had a key contact person to coordinate their care.

> **"[I] felt left on [my] own, all responsibility on myself for food, medication, appointments, care, liaising with many different people and services. No single point of contact – many different people dipped in and out but not one person coordinating assistance.**
>
> Died from cancer

This underlines the importance of delivering on the intention in the Quality Statement for Palliative and End of Life Care for a 24/7 single point of access to coordinated care, medication, and advice about end of life care. An implementation plan and timeline for delivering the aspirations of the Quality Statement within each Health Board is urgently needed. More integrated, innovative service models of care and system-wide collaboration should also be explored, learning from good practice examples which are reducing hospital admissions and delivering better outcomes for patients, such the REACT model in Bradford [14].

## No time to care

Survey respondents reported that staff across health and social care settings did not have enough time to provide care for dying people, or that support was not available for as long or as frequently as needed.

> **"The palliative care and district nurses and GP were great, but they only came a few times a week for half an hour.**
>
> Died from cancer

> **"While we have an excellent GP it was not always easy to get hold of him and this was very frustrating at times.**
>
> Died from dementia or Alzheimer's disease

Workforce pressures are well-evidenced across health and social care. GPs, nurses and healthcare assistants provide the majority of palliative care, often alongside a range of other services. While the number of people needing palliative and end of life care has risen steeply in Wales in recent years, the number of full-time GPs fell by more than 21% between 2013 and 2022 [15]. Nursing vacancies increased by 58% between 2021 and 2022 [16]. Future workforce planning must take account of the significant increase in need for palliative care forecast for the coming decades.

## Conversations about end of life care happen too late

Everyone in Wales with palliative care needs should be supported to participate in Advance and Future Care Planning (AFCP), allowing them the opportunity to discuss their needs, wishes and preferences for care at the end of life. These preferences should be recorded and regularly reviewed. Yet one in four (25%) people who died either probably or definitely did not know they might die because of their illness, according to their family members. More than one in three (36%) respondents said they only became aware that their loved one was dying in the last month of their life.

Though not everyone will want or be able to have conversations about their end of life wishes, all should be offered the opportunity. More than one in three (37%) respondents said healthcare professionals had not discussed death and dying with the person who died, while one in four (25%) were unsure. Though these conversations were more likely to have happened between healthcare professionals and the person's family (66%), some reported that healthcare professionals handled this poorly.

> **"One [hospital] doctor was incredibly harsh and lacked empathy when [we] were told my dad was extremely ill and probably in the final stages of life.**
>
> Died from a stroke

It is vital that health and care professionals have the time and skills required to facilitate AFCP. Electronic care coordination systems can support AFCP by incorporating needs and preferences within care records, which can then be shared amongst all those involved in a person's care with their consent.

# 4 Unpaid carers take on significant caregiving roles with little support

Unpaid carers – typically family and friends – play a critical role in end of life care, yet often their needs are not properly identified or supported. Most of the survey respondents had been involved in caring for the person who died: 54% helped them go to appointments or treatments, 56% helped with medical procedures, and 76% spent time 'on call' (ie being able to be contacted if needed), typically for more than 50 hours per week. Many respondents said they felt that they lacked the knowledge and skills but were unable to access sufficient support, with poor communication from professionals and care coordination a cause of significant stress.

> **"It was tough going as often, we were not sure if we were doing the right thing. We struggled to lift her, turn her, keep her clean and toileted. That's why we were desperate for carers to come and help – but there was a shortage of carers. So, we soldiered on, on our own, doing the best we could.**
>
> Died from cancer

In many cases carers were themselves frail or in poor health, particularly where the person who died had a diagnosis of dementia.

> **"[There] should be more recognition and support for the family members doing the care - my mother in this case, she felt isolated & depressed as [she] could only leave my father [for] short periods.**
>
> Died from dementia or Alzheimer's disease

## Case Study:
## Supporting people with late-stage dementia and their carers in Wales

Marie Curie's Dementia Care and Respite Service was launched in Swansea and Neath Port Talbot in October 2022 with funding from the West Glamorgan Regional Partnership Board. The service supports the growing number of people in the area living with late-stage dementia, enabling them to remain at home by providing high-quality care alongside proactive support for carers.

The service is comprised of two linked elements, tiered by patient acuity. The Dementia Companion Service, staffed by trained volunteers, provides people with lower levels of need and their carers with emotional support, practical help, and respite for up to three hours per week. The Dementia Respite Care Service, staffed by a Registered Nurse and Healthcare Assistants, provides people with more complex needs with assessments, assistance with daily activities, emotional support, and respite. People can be escalated and deescalated between service levels as needs change. This integration ensures resources are used efficiently by providing the most appropriate level of support.

The service has been well received, and anecdotal evidence suggests it has prevented the escalation of care to hospitals and care homes, allowing care to be provided at home in line with people's preferences.

With the number of older people living with dementia in Wales projected to increase by 70% between 2019 and 2040, supporting people with dementia and their carers will become an increasingly important part of end of life care.

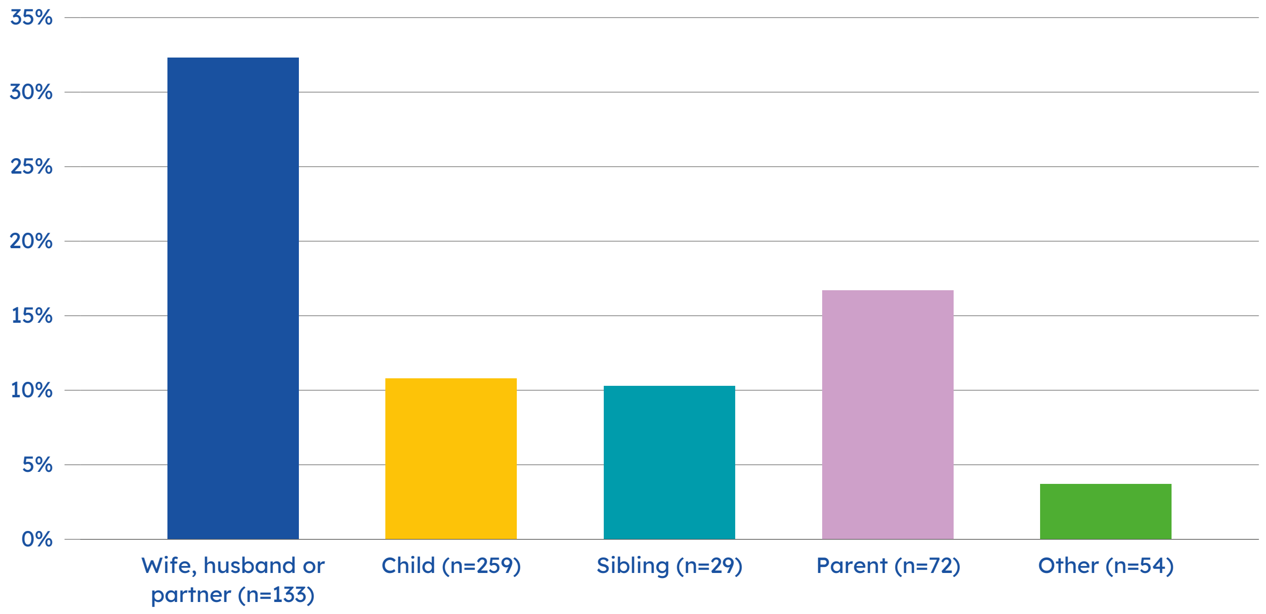
As well as being emotionally and physically difficult, caring for a relative at the end of life can also have a financial and professional impact. Of those respondents still in work, 14% took between 31 and 90 days paid or unpaid leave, while 6% quit or changed their jobs (including retiring early) to care for their loved one. Others reported a cut in wages as they reduced their hours to provide care.

> **“I’m still in the fog left after her loss. I’ve reduced my hours at work, I’m changed, life is changed.**
>
> Non-disturbed grief

## People with disturbed grief are not adequately supported

For some people, bereavement can result in disturbed grief: a debilitating grief response that causes psychiatric distress. One in six (16%) survey respondents met the criteria for disturbed grief, with a higher prevalence among younger respondents, female respondents, and those who were the spouse of the person who died.

**Prevalence of disturbed grief among respondents in Wales according to their relation to the person who died**



**(Source: Johansson et al., 2024, p. 110)**

Respondents who were unhappy with aspects of care or who felt that healthcare professionals had not listened to them or communicated well also had higher levels of disturbed grief.

> **“I have contemplated making a complaint many times but the grief has been so overwhelming that**

> **I have needed to come to terms with all that has happened. The pain and guilt never leaves me.**
>
> Disturbed grief

Nearly four in five (79%) of those who met the criteria for disturbed grief had not accessed bereavement support, suggesting significant unmet need.

# 5 Making a good end of life experience possible for everyone

Many of the quotes and findings from the research make for upsetting and sometimes shocking reading, however there were also numerous examples of positive end of life care experiences.

> **“Mum and I were lucky to have a positive experience from some of the most amazing people I have ever met. These people (staff) became like family as I visited nearly every day for 6 years.**
>
> Died from dementia or Alzheimer’s disease

> **“The care team at the hospital where he died was amazing. Credit to the doctors and nurses. They walked us through step by step and let us know at every turn what was going on with him.**
>
> Died from a lung condition

In Wales, the Quality Statement for Palliative and End of Life Care has already described the support that everyone who needs palliative and end of life care should receive. We know what good end of life care looks like, but there is not yet a clear plan for how the Quality Statement will be implemented. Addressing this implementation gap should be an urgent priority for the Welsh Government and Health Boards.

# Policy recommendations

| | Recommendation | For action by |
|---|---|---|
| **Making a good end of life experience possible for all** | An implementation plan and monitoring framework which sets out how the aspirations of the Quality Statement and forthcoming service specification will be delivered within each Health Board must be developed. | • Welsh Government |
| **Better support for pain and other symptoms** | Local arrangements for end of life care prescribing, including the commissioning and use of Just in Case packs, should be reviewed to identify and address gaps and inequities in access. | • Health Boards |
| | Community pharmacy services should be commissioned to provide a standardised set of palliative care medications and make them consistently available 24/7. | • Health Boards |
| | Palliative and end of life care should be embedded across all relevant strategic programmes, clinical networks, and condition-specific Quality Statements. | • Welsh Government |
| **Delivering 24/7 community care** | Initiatives to increase community care capacity must be delivered, with learnings from the implementation of 'Further Faster' and other initiatives shared, and recurrent ringfenced funding to support community palliative and end of life care capacity guaranteed into the future. | • Welsh Government<br>• Health Boards<br>• Regional Partnership Boards |
| | A data-driven, holistic process for assessing population need for and experiences of palliative and end of life care should be developed and rolled out across Wales, enabling a more joined-up approach to commissioning which includes both statutory and third sector partners. | • Welsh Government<br>• NHS Executive<br>• DHCW |

| | | |
|---|---|---|
| **Integrated services and timely, coordinated care** | Electronic care co-ordination systems should be resourced in ways that incentivise their sustained use and sharing with progress on the use and availability of shared records, including advance care planning, being audited regularly. | • Welsh Government<br>• NHS Executive<br>• DHCW |
| | A palliative and end of life care workforce plan should be published based on independently verified projections of current and future demand. | • Welsh Government<br>• NHS Executive |
| | All health and care professionals should be funded to receive training in and have time to follow clear national guidance on advance and future care planning. | • HEIW<br>• Social Care Wales |
| **Support for unpaid carers** | Models for providing education to end of life carers should be delivered, learning from good practice examples such as Last Aid training in Scotland. | • Welsh Government<br>• Health Boards<br>• Local Authorities |
| | A pro-forma of key healthcare information required by carers should be developed and adopted as part of routine care for everyone with an advanced illness, and as part of the support available to everyone caring for someone with a terminal illness. | • Health Boards<br>• Local Authorities |
| | The Carer Support Needs Assessment Tool (CSNAT) should be piloted as part of the package of care for people at the end of life, to improve carer needs assessment and support. | • NHS Executive<br>• Health Boards<br>• Primary Care<br>• Local Authorities |

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