West Wales Carers Strategy: Survey Report

wwcp
Partneriaeth Gofal Gorllewin Cymru
West Wales Care Partnership

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol
Hywel Dda
University Health Board

Cyngor Sir Penfro - Pembrokeshire County Council

Cyngor Sir
CEREDIGION
County Council

Cyngor Sir Gâr
Carmarthenshire
County Council

Contents

Executive summary

An on-line survey was developed by the West Wales Carers Development Group (WWCDG) to seek feedback about the views and experiences of unpaid carers, or professionals/organisations working with unpaid Carers. The consultation ran from 11th May – 14th June 2020 and the information gathered will be used to inform the development of a Regional Partnership Board Carers Strategy.

In summary:

- A total of 558 people engaged with the survey (though the response rate for individual questions varied).
- 46% of respondents were from Pembrokeshire, 35% from Carmarthenshire, 18% from Ceredigion and 2% from outside of the region.
- 78% of respondents were female, whilst 22% were male.
- Many of the respondents were aged 45 – 64 (46%). Responses for other age categories were: 65 and over (19%); 18 or under (18%); with the remainder of respondents in the range of different age categories between 19 – 44.
- 96% of respondents were white (British, Irish, any other white background), whilst the remainder of respondents were of other ethnicity.

Theme 1: Identification of Carers

- 21% of respondents (23% of Pembrokeshire respondents) confirmed that they have had a conversation with an NHS, social care or third sector professional about what to do if the condition of the person they care for deteriorates or they are no longer able or willing to provide care for them.
- When asked about the impact of missing out on support, the most frequent response (177 of the 365 respondents who answered the question) was that they suffered from stress or anxiety. This was followed by a negative impact on finances and an increased strain on their relationship with other people.
- Apart from 'putting a strain on their relationship with the person they care for', respondents in the 35 – 44 age category had the highest propensity to agree with all of the statements. This suggests that carers in this age group are facing the most serious consequences of caring responsibilities.
- Asked if they or the person/people cared for use any technology to support care and caring, 76% of those aged 35-44 say they used the internet as a source of information, in comparison to 64% of the overall sample.
- Those aged 75 – 84 are more likely to say they use technology for vital signs monitoring (24% of this age group, compared with 11% overall) and remote health care (32% of this age group, compared with 18% overall).

Theme 2: Supporting Life Alongside Caring

- When questioned about circumstances in addition to a caring role (Q18; 360 responses), the majority of respondents were either retired (30%), employed full-time (26%) or not in paid work (21%).
- With reference to the respondent's relationship to the person being cared for (359 responses), those caring for a partner are most likely to be retired (50%). Furthermore, 40% of male carers are retired, compared to 30% for respondents overall.
- Asked whether caring has had an impact on their physical health and mental well-being 64% (of 362 responses) agreed. Respondents who are former carers are even more likely – at 75% - to think caring had a negative effect (12 of 16 such respondents; though consideration must be given to the relatively low numbers). Male carers were marginally less likely to report a negative impact at 59% (36 of 61 male respondents).
- Asked whether there was anything else respondents' thought important about supporting life alongside caring, including what may help to better balance the caring role, access to appropriate respite was by far the most frequently cited issue.

Theme 3: Providing Information, Advice and Assistance

- Asked whether they had seen any information produced by their local authority, health board or third sector organisations that would help their role as carer (363 responses), 37% of respondents had seen such information and thought it was either useful (24%) or very useful (13%); 17% had seen it and didn't think it useful; 19% were not sure whether they had seen such information (42% of those 26-34) and 28% had not seen any information (39% of those 26-34).
- With regards to accessing the Carers Information Service (CIS) in the last 12 months, of the 363 responses, 75% had not accessed these (80% for Pembrokeshire respondents; 92% for carers aged 26-34).
- The most frequently accessed information was 'booklets and factsheets' (10% of respondents overall; 25% of Ceredigion respondents) and 'by telephone' (8% of respondents).
- Asked whether they'd had a carer's assessment or a review of their assessment in the last 12 months, the most frequent response was 'no' (81% overall; although this was lower at 57% for those 75-84, and for Ceredigion at 67%); followed by 'yes and waited less than 6 months' (11% overall; 24% Ceredigion); 'yes and waited more than 6 months' (6%); and finally 'awaiting assessment or review' (2%).
- The extent to which respondents felt that the assessment process and subsequent consideration of the care and support needs took account of a range of considerations is considered. In general, it can be said that the balance of opinion is against the sufficiency of the assessment process in taking account of the listed aspects: 'not properly considered' was the most frequent response in every case.

Covid-19

- The **coronavirus outbreak** has presented specific circumstances both in terms of direct infection and the measures implemented to minimise disease transmission (i.e., the ‘lockdown’). A differential impact on carers was considered likely; hence the inclusion of a specific question (how best to support carers through the pandemic) to seek comment from carers and relevant support organisations.

West Wales Carers Strategy: Survey Report

Introduction

The West Wales Carers Development Group (WWCDG) is developing a strategy for unpaid carers. In so doing, the Group will have reference to the direction being set by the Welsh Government Ministerial Advisory Group for Carers (who are shaping a national framework for carers), the regional Area Plan, as well as the strategic plans of constituent organisations within the Regional Partnership Board (the West Wales Care Partnership). The Strategy also needs to reflect and draw on relevant evidence. This includes the regional Population Assessment and feedback from range of pre-existing engagement exercises. The WWCDG took the view that it was useful to undertake further engagement at this juncture to a) bolster and supplement existing engagement and research and b) to reflect the unique circumstances relating to the Covid-19 'lockdown' that may well exacerbate issues facing carers – such as possible increased isolation, and reduced opportunities for replacement care.

Method

The WWCDG established a small project team who devised a survey (see appendix 1), composed in part from questions featured in recent regional (west Wales) and national (UK) carer surveys, but based on the three themes identified by the Welsh Government (WG): 'identification of carers'; 'supporting life alongside caring'; and 'providing information, advice and assistance'. These themes have been adopted within the existing West Wales delivery plan for unpaid carers.

Due in part to the social distancing implications of the response to the coronavirus, it was decided that an online survey offered the greatest opportunity for engaging the widest range of views from interested parties, and so maximising the response rate.

Extensive effort was made to ensure a strong response through dissemination by members of the West Wales Carer's Development Group, carer networks members and relevant carer organisations (see Appendix 2 for the full list). This list was augmented as the project team were alerted to additional organisations and networks and this increased list is a notable research output in itself.

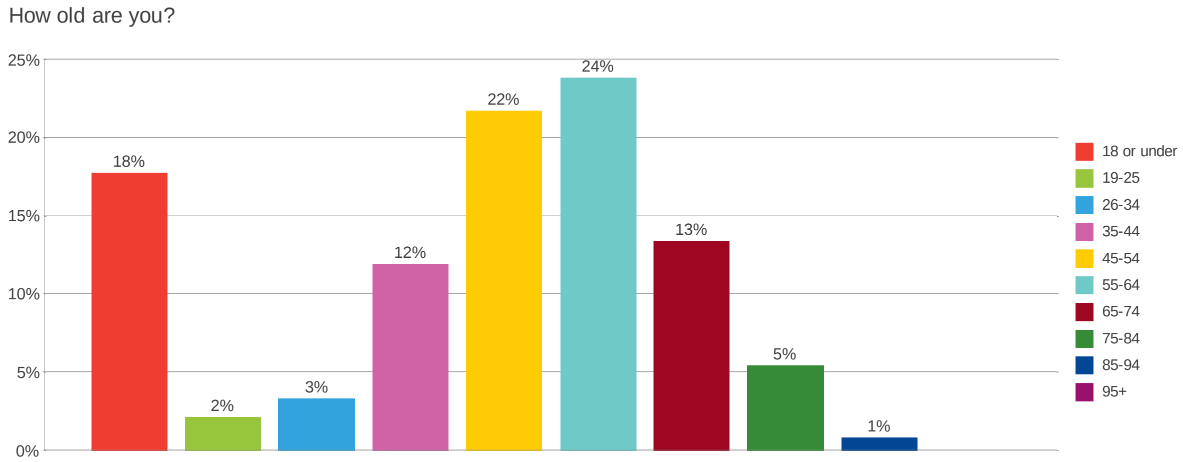
Special considerations were made in targeting young carers to engage with the survey, which included the amendment of the free text response questions at the end of each section in tailoring the questions to allow young carers to more easily participate.

The consultation exercise ran from 11th May until 14th June 2020.

Respondent profile

A total of 558 responses were received, of which 88% currently care for a person or persons; the remainders of respondents were either former carers (4%), organisations that provide support to carers (6%) or considered in another role (2%).

In terms of **age demographics**, 46% of respondents are in the 45 – 64 category, 19% are 65 and over, and 18% or under category (18%). The full age profile can be seen below:



> ***NOTE:*** *In considering the analysis from this point, it is important to note that respondents aged 18 or under only answered the free text response questions at the end of each of the three themes and the two final free text response questions at the end of the survey.*

Regarding **residence**, 46% of respondents were from Pembrokeshire, whilst 35% of respondents were from Carmarthenshire, 18% from Ceredigion and 2% from outside of the region. The figures for Carmarthenshire and Pembrokeshire are a reversal of what would be expected on the basis of population share.

With regards to the **gender split** of respondents, 78% were female whilst 22% were male. 96% of respondents were white (British, Irish, any other white background), whilst the remainder of respondents were of other ethnicity.

For **numbers cared for**, 74% of respondents cared for one person, 19% cared for two, whilst the remainder of the respondents cared for three or more people.

In terms of **relationship to the cared for**, the majority of respondents were either the parent (32%) or partner (27%) of the person they provide care for, with 14% caring for an adult child (over 18) or a sibling (8%).

The **age ranges** for the person who is **cared for** are 20% under 18, 43% are in the age categories between 19 – 64, a further 33% in the 65 – 74 range, 18% in the

75 – 84 category and 20% in the 85 – 94 age range; this indicates that over two-thirds of respondents care for at least 1 person over the age of 65 (71%)[1].

The three most common **care and support needs** indicated by the respondents are physical disability or mobility problems (58%), long-term or serious illness or condition (47%) and mental health - including anxiety and depression (28%).

Responses to Theme 1: Identification of Carers

Out of **365 respondents**, 21% confirmed that they have **had a conversation with an NHS, social care or third sector professional about what to do if the condition of the person they care for deteriorates or they are no longer able or willing to provide care for them**, whilst 79% had not (Q10)**.**

Of the **78 respondents** who confirmed they had this conversation, those in the age categories of 55 and over accounted for the majority - making up of 64% of 'yes' respondents (50 of 78 responses). Of the **287** who answered 'no', 68% of respondents were aged between 19 – 54 (138 of 287 responses). Pembrokeshire respondents are slightly more likely to confirm they have had this conversation - at 23% compared to the average of 21%. Males account for a higher proportion in confirming they had had this conversation - at 31% - whilst this was only the case for 20% of females.

When asked **how long it took to realise that you had taken on a caring role** (Q11; 365 responses), only a third of respondents at 38% felt this happened either immediately or within six months or less, whilst 16% of respondents felt it took over a decade before realisation (over 49% of those not in paid work).

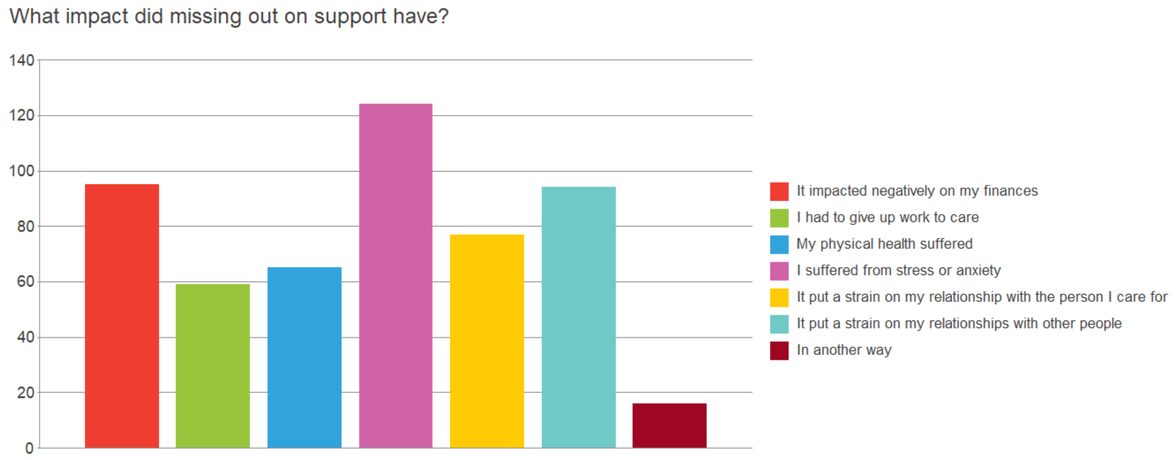
Asked if they felt that they **missed out on support as a result of not recognising they were a carer** (Q12; 361 responses), half of the respondents (49%) agreed, whilst 29% said they did not and 22% were unsure; 18% of those who missed out felt they missed out on financial support (40% of those undertaking voluntary work), whilst 31% felt they missed out on practical support (41% of those not in paid work). The 26 – 34 age group were very likely to say that they had missed out on practical support at 67% (compared to the overall for all respondents at 31%)[2].

---

[1] The percentages exceed 100 because some respondents care for more than 1 person and those respondents therefore made more than one response.

[2] Care with interpretation needs to be taken with relatively low number (8 responses of 12).

When asked about the **impact of missing out on support** (Q13; 177 responses), the majority of respondents felt that they suffered from stress or anxiety, followed by a negative impact on finances and an increased strain on their relationship with other people.



Apart from putting a strain on their relationship with the person they care for (joint second), respondents in the 35 – 44 age categories had the highest propensity to agree with all of the statements. This suggests that carers in this age group are facing the most serious consequences of caring responsibilities.

With regards to the **kind of support carers are receiving in the region** (Q15; 359 responses), respondents indicated that the most common form of support which they received or bought includes: equipment in the home of the person they care for (43%), help from family or friends (30%) and technology like alarms, sensors or remote monitoring to help with caring (25%); however, it is worth nothing that the fourth most common answer ('none' - 24%) indicated that respondents had received or bought no equipment to support their caring needs; this could indicate that there is an unmet need for support.

Do you receive or buy any practical support with caring?

Total number of responses:	**359**
Equipment in the home of the person I care for (like hoists, grab rails or easy-grip handles on taps)	154
Technology like alarms, sensors or remote monitoring to help with caring	88
Practical support from care workers coming in to help	62
Use of a day centre for older/disabled people	29
Help managing or co-ordinating care	16
A break for me from caring	49
Specialist childcare for a disabled child	11
Extra childcare for children who are not disabled (which helps me to care for my other loved ones)	5
A Motability vehicle	62
Help with other household chores (like shopping or cleaning)	43
'Live in' support (someone who is paid to live with us/the disabled/older person I care for to provide care and support)	4
Help from family or friends	107
Occasional use of a care home	15
Occasional use of a hospice	5
The person I care for lives in a care home	2
None	85

Other	25

When asked if **they or the person/people cared for use any technology to support care and caring** (Q16; 365 responses), 24% of respondents indicated they did not use any form of technology to support their caring needs. Of those that confirmed they did use technology, 64% of respondents use the internet as a source of information, whilst 35% use the internet as a form of communication or online support; a further 18% of respondents confirmed the use of remote health care such as online GP appointments, repeat prescriptions, online video consultations and online mental health resources.

Of those that use the internet as a source of information, the most common age category is those aged 35 – 44 (76% against 64% for all respondents).

Those 75 – 84 are most likely to use technology for vital signs monitoring (24%) against 11% overall) and remote health care (32% against 18% overall)[3]

Respondents were given an opportunity to give **general comment on Theme One** (Q17). The following key issues were raised (total comments: 167):

- **Identifying and providing additional support to carers was the most frequently identified issue.**
- Work together, good communication, listen to carers.
- Parents don't see themselves as carers.
- Increased sharing of information with professionals.
- Communication throughout the multi-disciplinary teams needs to be more effective.
- Working as one system to ensure all health professionals know of a carer's role and the difficulties this brings.
- Recognition of carers having a 'voice'.
- Having resources that can help carers remain able to work and be a carer at the same time.
- Make better use of social media channels in identifying and providing information to carers.
- Creation of accessible information on multiple platforms, e.g. pamphlets / posters in GP surgeries, radio adverts, social media etc.
- Educating / highlighting within schools; resources to provide young carers respite to allow them time out.
- Make sure teachers understand; invite someone to deliver a talk in schools, provide posters etc.
- Keep in regular contact with the carer to make sure they don't burn out.

52 responses were made by those **under 19**:

- Visit schools; it would be better if teachers understood more.

---

[3] Care with interpretation needs to be taken with relatively low number (8 and 6 respectively of 25).

- Use the internet more; Facebook is great for getting information; be visible on social media / TV adverts.
- Too young for Facebook, but letters / text messages would be good.
- Someone to text or phone if I need to have a chat.
- Make sure that people know what a young carer is – use posters, leaflets, websites and social media.
- Someone to talk to, and social outings with other young carers.
- Let the doctors speak to me as well as my dad.

25 comments were made by **organisations.** The key issues were:

- More needs to be done in local press and advertising of the third sector agencies, because unless you become a carer you wouldn’t necessarily know about any of the services.
- This is particularly relevant to carers who don't do any 'hands on' caring tasks as such but there is considerable emotional impact in living with a loved one who experiences alcohol and other drug dependence.
- Increased sharing of information with professionals - schools are often unaware of medical/social needs and this information is not always forthcoming - how could this be addressed whilst being mindful of confidentiality?
- The use of local knowledge to identify ‘unidentified’ carers.
- Carers often do not identify with the term ‘carer’ as they view it as “just something you do” almost a duty to look after their loved ones.
- Visible Carers Information Services in hospitals.
- The COVID 19 pandemic has highlighted the critical importance and role digital technology must compliment the role of a Carer. It is important that entry level digital skills and confidence training is provided to everyone who performs a carers role.
- Facebook, Instagram, Twitter information from agencies; Facebook live or hangout meeting to talk to someone.
- There is good support within many schools and colleges including Area 43 counselling, Schools Based Youth Workers and College Mentors; further work is needed with some schools, especially primary schools, to ensure that all education settings are at the same level.
- As highlighted many times, despite GP surgeries across the County having the IiC award, we are not seeing referrals from them. Young people report that they are not asked if they are a young carer even when accompanying a parent with a disability to an appointment. There is further work needed to improve this.

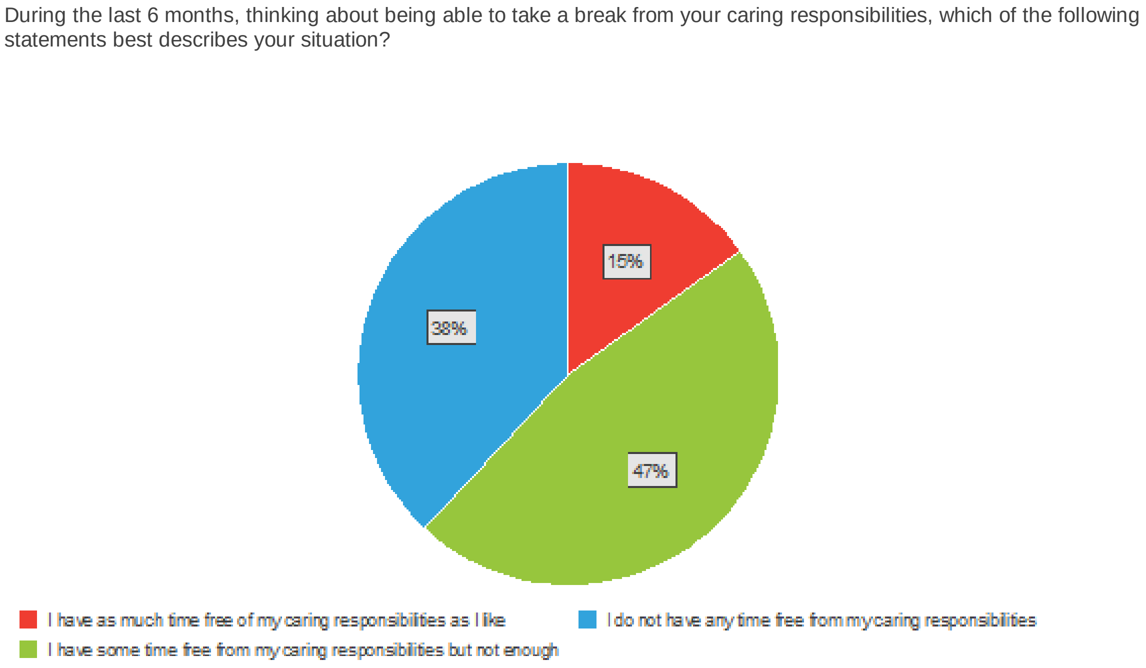
Responses to Theme 2: Supporting Life Alongside Caring

When questioned about **circumstances in addition to a caring role** (Q18; 360 responses), many respondents were either retired (30%), employed full-time (26%) or not in paid work (21%). Of those who confirmed full-time employment (92 responses), the majority of respondents were in the age categories between 35 – 64 (91%). Those in the 35 – 54 age categories accounted for most respondents in education (75%); however, it must be noted that under 19s only completed free text responses and therefore did not complete this question. Those not in paid work were predominantly in the 45 – 64 age categories (62%). Retirees accounted for 30% of overall respondents.

The majority of respondents to this question care for 1 person (268 responses – 25%), whilst those that care for 3 or more people are either employed full-time (50%), not in paid work (33%) or considered in another role (17%).

With reference to the respondent's relationship to the person being cared for (359 responses), those caring for a partner are most likely to be retired (50%). Furthermore, male carers are more likely to be retired (44% against an overall of 30%).

The results for the following question (Q19; 358 responses) are shown in the pie chart below: **'during the last 6 months, thinking about being able to take a break from your caring responsibilities, which of the following statements best describes your situation?'**:



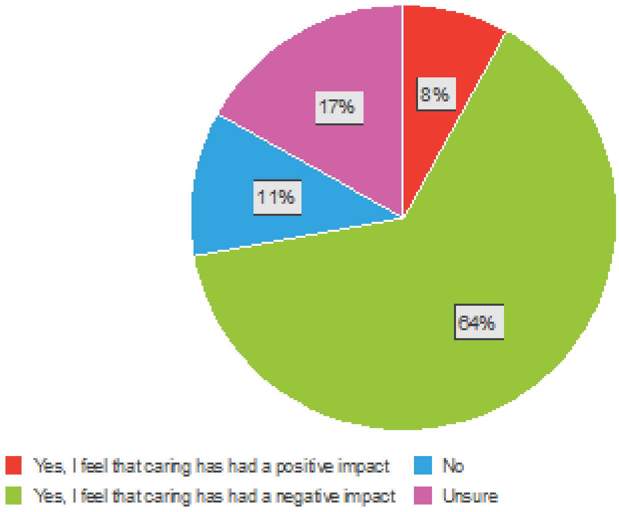
That 38% report not having any time away from caring, suggests that caring may become unsustainable for these respondents over an extended period of time.

Interestingly, the percentage was higher for those aged 35 – 44 (53 responses) at 59%. The results also suggest that the likelihood of reporting not having any time increases by numbers cared for: 1 cared for = 38% (92 responses); 2 = 38% (25); 3 = 68% (13); and more than 3 = 71% (5). Surprisingly, the figure for those saying they have insufficient time away from caring is higher for those not in paid work (48% compared to 38% overall); this could indicate that work itself can be viewed as a form of respite and time away from caring.

118 further comments were made in relation to the question above:

- Support is very difficult to get; especially during 'lockdown'.
- Respite is lacking but care home and day centre provision is greatly appreciated.
- Schooling (suspended during lockdown) usually provides a break.
- Carers having to financially support the cared for and suffer financially through often being unable to work.
- Being sole carer (without support) often means people have insufficient time.
- Breaks highly valued (e.g., YAC Project).

Respondents were asked whether **caring has had an impact on their physical health and mental well-being** (Q21; 362 responses). The chart below suggests a negative impact in general:



Do you feel that caring has had an impact on your physical health and mental well-being?

Respondents who are former carers are even more likely – at 75% - to think caring had a negative effect (12 of 16 such respondents, though consideration must be given to the relatively low numbers). 72% of those who were not in paid work (55 responses) reported a negative impact, which is again higher than the overall result of 64%. Male carers were marginally less likely to report a negative impact at 59% (36 of 61 male respondents).

138 further comments were made in relation to the above question. The key themes were:

- Mental health implications of caring: stressed, worried, sleep problems, depressed and anxious.
- Exhaustion and run down; constantly on call.
- Difficulties in accessing services for the cared for – creates added pressure and challenges the sustainability of providing unpaid care.
- Isolation and loneliness: reduced social opportunities; no time for friendships.
- Sense of loss as the health of the cared for person deteriorates.
- Carers feeling they have lost their identity (beyond being a carer).
- Danger of losing sight of the relationship (e.g., husband, child, mother) as functional caring role predominates.
- Employment: leaving work or taking part time or less senior positions; unsympathetic managers.
- Role is also inspiring, rewarding and positive.

The final question (Q23) under Theme 2 asked whether there was anything else respondents' thought important about supporting life alongside caring, including what may help to better balance the caring role.

A total of 224 comments were made:

- Respite and replacement care are critical for resilience: available, both flexible and scheduled, affordable, suitable (e.g., play provision for young cared for people, day centres, residential or domiciliary care, personal assistant, offered in the cared for person's home, etc). Respite to be offered pre-emptively – before crisis. **Respite was by far the most frequently cited issue.**
- Befriending/ company for cared for person: people don't necessarily (just) need replacement care.
- Time away from caring (linked to respite).
- Support services for carers 'inadequate' and just 'pay lip service': information is available (and duplicated) but actual services are lacking.
- Difficulties accessing support for cared for people exacerbates impact on carers. Having a single contact who can navigate the system would help.
- More support with carer mental health; bereavement services should support carers anticipating death of cared for.
- More local provision of support for complex needs.
- Carers undertaking paid work have difficulty where services for cared for people are run on a '9-5' weekday basis: including hospital discharge, day centres, GPs, etc.
- Financial position restricts options, including when taking time away from caring. Difficulties balancing paid work with caring noted.
- Greater understanding of the carer role; particularly amongst employers.
- Peer support and people to talk to.

- Trusted help with cared for. The importance of consistency of paid carers was stressed.
- The carers grant was a great help in accessing activities supportive of wellbeing.

47 responses were made by those **under 19**:

- More time away from caring doing relaxing and fun activities, including the young carers project.
- More respite care for cared for, including Holly House.
- Where siblings are cared for, freeing up time to spend with parents is valued.
- More young carer groups.
- Better accessible environments so easier to get out and about with cared for person.

22 comments were made by **organisations**. The key issues were:

- Respite and replacement care are critical for resilience: available, both flexible and scheduled, affordable, suitable (e.g., play provision for young cared for people), offered in the cared for person's home. Respite was the most frequently cited issue.
- Breaks for carers – work with businesses to offer discounts (spas, sports clubs, hotels, etc). Breaks for young carers: including young carer clubs.
- Technology offers opportunities: assistive technology (for cared for); virtual reality, gaming, support, etc (breaks for the carer).
- Many carers don't have time for a life outside caring.
- Lack of awareness of support available.
- Coronavirus lockdown is increasing the amount of care given by carers.
- Opportunities for carers and cared for – support events that are entertaining and not just about information.
- Greater engagement and support by employers.
- Service delivery impacts upon carer workload, particularly if delayed (for example, waiting lists for housing adaptations).

<u>Responses to Theme 3: Providing Information, Advice and Assistance</u>

Respondents were asked whether they had seen **any information produced by their local authority, health board or third sector organisation**s that would help their role as carer (Q24; 363 responses). 37% had seen such information and thought it was either useful (24%) or very useful (13%); 17% had seen it and didn't think it useful; 19% were not sure whether they had seen such information (42% for those 26-34) and 28% had not seen any information (39% for those 26-34).

In terms of county variations, Ceredigion respondents were more likely to have seen the information and found it either useful or very useful (56%), compared to Carmarthenshire (36%) or Pembrokeshire (33%). 30% of Carmarthenshire and Pembrokeshire respondents had <u>not</u> seen such information, whereas for Ceredigion, the figure is much lower, at 11% - suggesting greater penetration in this county.

68 comments were made about the **information that was most useful**. The most frequently cited response was 'carer newsletter', but the following were also highlighted:

- Information from GPs – posters, leaflets and emails.
- Carer information packs, as distributed by social workers.
- Lists of support networks and organisations.
- Information about available support (including financial) and legal rights.

In relation to the question about **accessing the Carers Information Service (CIS)** in the last 12 months (Q26), of the 363 responses, 75% had not accessed these (80% for Pembrokeshire respondents; 92% for carers aged 26-34). The most frequently accessed were 'booklets and factsheets' (10% of respondents; 25% of Ceredigion respondents) and 'telephone' (8% of respondents).

For the 90 who had accessed CIS, a range of benefits was highlighted[4]:

- Practical support and how to access it (44%).
- Knowledge of rights (32%; 57% for those 75-84).
- Knowledge of benefits and financial help (31%; 51% for those 35-44).
- Help in getting practical support (21%; 86% for those 75-84).
- Help in managing the caring role (20%).

16% of respondents who contacted the CIS said they were not helped and a further 16% were not yet sure how they had been helped.

Respondents were asked whether they'd had a **carer's assessment or a review of their assessment in the last 12 months** (Q28). The most frequent response was 'no' (81%; though this was lower for Ceredigion respondents at 67%, and 57% for those aged 75-84), followed by 'yes and waited less than 6 months' (11% overall; 24% Ceredigion respondents); 'yes and waited more than 6 months' (6%); and finally 'awaiting assessment or review' (2%).

The extent to which respondents felt that the **assessment process and subsequent consideration of the care and support needs** (Q29) took account of a range of considerations is considered next. In general, it can be said that the balance of opinion is against the sufficiency of the assessment process to take account of the listed aspects: 'not properly considered' was the most frequent response in every case, as shown below in rank order:

		Not properly considered	Some but insufficient	Thoroughly considered
If relevant, the support you need as the person you care for or you transition from children's to adult services	62	62.90%	12.90%	24.20%

---

[4] multi-response - %=of the 90 respondents

The support you need to juggle care with work or return to work	113	61.90%	19.50%	18.60%
The support you need to juggle care with training or education	96	59.40%	20.80%	19.80%
Your ability to maintain relationships with family and friends	122	58.20%	24.60%	17.20%
Your ability to have time to yourself	124	58.10%	24.20%	17.70%
What needs to be put in place for the person you support in case of an emergency	132	57.60%	23.50%	18.90%
Other	38	55.30%	15.80%	28.90%
The need to have regular breaks from caring	129	53.50%	27.10%	19.40%
The support you need to provide care for others (i.e. a non-disabled child or someone else with care or support needs)	126	53.20%	23.00%	23.80%
The support you need to look after your own mental and physical health alongside caring	144	52.80%	25.00%	22.20%
The suitability of your housing for continuing your caring role	122	39.30%	25.40%	**35.20%**
Your ability and willingness to provide care	143	39.20%	27.30%	**33.60%**

The above shows that respondents are more likely to agree that the assessment process 'thoroughly considers' their needs for 'housing' (35%) and 'ability and willingness to provide care' (34%) - see bold.

Respondents were given an opportunity to give **general comment on Theme Three** (Q30). The following key issues were raised (total comments: 212):

- 'Not having had an assessment' is frequently cited.
- 'One stop shop' critical; not 'passed from pillar to post' – were often referenced.
- Frequent comment about information needing to be backed by availability of acceptable and appropriate services.
- Perception of carer needs as a secondary consideration (after cared for); feeling carers are 'left to it'. Reference made to support services for cared for not embracing carer dimension.
- Face to face support is important.
- Growing importance of websites and social media in highlighting available services.
- Group meetings and peer support highly valued; could a network for working carers be established?
- Improved training for keyworkers undertaking carer assessments; carers to be employed as assessors (better grounding).
- Self-help courses highlighted; 12-week occupational department course referenced.
- Emotional support and mental health training, including where carers support a person with substance misuse issues.
- Many services are not accessible to those in work/ in education (timing).

- Carers should have proactive calls (e.g., extend the Delta Wellbeing project).

47 comments were made by respondents aged **18 and under**:

- A need for first aid training.
- Mental health support for young carers.
- Online information is best (including Facebook and Instagram).
- More peer support would be appreciated.

19 comments were made by **organisations** and the following issues were highlighted:

- A single vision/ approach is needed to carer support across the Region.
- Benefits of a single point of initial contact stressed; information should include dementia, mental health and domestic abuse.
- Information is needed in a variety of forms – some don't use a computer.
- Personal contact is key (phone, face to face, including outreach) - caring is stressful which can make processing information harder.
- Person-centred approach: right information at the right time.
- Advocacy critical in ensuring access to support services.
- Emotional support for carers is needed to support mental health; especially for those under the threshold for services.
- Importance of peer support and support groups.
- Reaching 'hidden' carers is an issue – population-wide dissemination is necessary.

<u>Anything else? Any other comments</u> (Q31)

172 comments were made relating to the following themes:

- Services may be inadequate, particularly in rural areas. Sufficiency of breaks and respite critical; service sometimes appears 'crisis-driven'.
- Balancing work/ education, family and caring puts a lot of stress in carers – sufficient breaks essential for sustained support/ preventing 'burn-out'.
- Importance of relevant information (e.g., carers information packs). 24-hour single point of contact needed.
- Feeling carers left to 'muddle through'.
- Ensuring carers have a voice and are listened to. Carers need recognition.
- Routine development of emergency plans for when carers unable to care.
- Suggested development of a facility for breaks by carer or cared for (including day centres).
- Advice and advocacy critical in securing rights.
- More could be done to ensure employers support staff who are also carers.
- Support system can be complex and hard to navigate.
- Early identification of carers critical as this unlocks support.
- 'Transition' (between children and adult services) requires greater support.
- Better coordination of support by local authorities and health.

47 comments were made by people **18 and under**. The key themes were:

- More time away from caring, with a variety of activities and times offered.

- Benefits of peer support stressed – young carer groups. Support for further provision.
- Schools need to do more for young carers, including greater understanding.

Organisations (13 responses) reported the following key issues:
- Carers are stressed and need greater access to suitable breaks.
- Recognition necessary for the support given by third sector organisations. Consideration given to further investment by public sector.
- Carer Assessment needs redesign and positive outcomes enhanced (including signposting to support, activities, etc). Issues raised as to timeliness.
- Specific support needed for younger carers – mainstream services designed for adults and often, older adults.
- Grasp the opportunities presented by online shift during Covid-19. Specialist third sector organisations/ projects like Digital Communities Wales can help.

Coronavirus (Q32)

The coronavirus outbreak has presented specific circumstances both in terms of direct infection and the measures implemented to minimise disease transmission (i.e., the 'lockdown'). A differential impact on carers was considered likely; hence the inclusion of a specific question (how best to support carers through the pandemic) to seek comment from carers and relevant support organisations.

Overall, 238 comments were made. The following were stressed:
- 'Lockdown' = increasing pressures on carers due to 'shielding' requirements. Carers felt they have no choice but to continue supporting. However, some cared for people are benefitting from more contact time with their unpaid carer.
- 'Keeping in touch' calls, emails, video calls essential; virtual contact with support and peer groups highly valued; supports carer mental health and emotional wellbeing.
- Practical support via helpline – shopping, collecting medications, etc.
- Importance of antibody testing in re-establishing contact.
- Breaks/ respite stressed as important, though difficulties acknowledged.
- Consistency of respite carers can help reduce spread.
- Targeting increased support at carers who are most in need, or most isolated.
- Concerns about implications if either carer, or cared for, have Covid-19.
- Classifying carers as key workers would help (free parking, early morning shopping); disquiet that paid carers have been given £500 by Welsh Government, but unpaid carers have not been similarly recognised.
- Financial issues: some carers have had to take unpaid leave, as other care has to be declined (shielding).
- Lockdown has made caring easier – working from home, don't have to prepare the children for school, no expectation to go out.

The following issues were raised by respondents **18 and under** (53 responses):

- Concerns about falling behind with schoolwork and worry about schools being understanding of caring responsibilities.
- Young carers service has provided support, including one to one.
- Wellbeing pack/ bag well received.
- Services to get in touch in timely fashion.
- After lockdown, more time to do things away from caring. One respondent hoped for a big post-lockdown party!

Organisations made the following points (20 responses):

- Carers are feeling isolated. Regular contact is essential whether by phone or online (including Zoom). Courtesy (proactive) check in calls are important.
- Carers are under unsustainable pressure. Support will be required following the easing of 'lockdown' to support the recovery of carers.
- Further exploration of online options: interactive groups, webinars, toolkits and training.

Next steps

The information summarised in this report from survey participants will be consider alongside additional feedback gained through workshops and other engagement activities which have been undertaken over the past 18-months, to inform the development of a Regional Carers Strategy. The final strategy, which is intended to provide direction for the next 3-5 years, will be presented to the West Wales Care Partnership, the regional partnership board in the Hywel Dda area, in autumn 2020.

Appendix 1

Carer Strategy Survey

The Welsh Government defines carers as: "anyone of any age, who provides unpaid care and support to a relative, friend or neighbour who is disabled, physically or mentally ill, or affected by substance misuse".

The Health and Social Care organisations in west Wales are developing a regional strategy for unpaid carers which will be endorsed by the West Wales Regional Partnership Board. This survey is based on the three key themes identified by the Welsh Government:

- **Identification of carers**
- **Supporting life alongside caring**
- **Providing information, advice and assistance (IAA)**

We would be grateful if you could fill out this confidential survey so we can work out how best we can support unpaid carers. Your responses will be used to shape the actions within our strategy.

1 **Are you?**

- A Carer
- Former Carer
- An organisation that provides support to carers
- Other

Please specify:

____

Name of your organisation:

____

This survey has been designed for individual carers and questions are phrased accordingly, but please answer from the perspective of your organisation.

2 **How old are you?**

- 18 or under
- 19-25
- 26-34
- 35-44
- 45-54
- 55-64
- 65-74
- 75-84
- 85-94
- 95+

3 **Which county do you live in?**

- Carmarthenshire
- Ceredigion
- Pembrokeshire
- Other

Please state:

____

____

4 **What is your Gender?**

- Female
- Male
- Other

Please specify:

____

____

5 **To which of these groups do you consider you belong?**

- White (British, Irish, any other white background)
- Mixed (White and Black Caribbean, White and Black African, White and Asian, any other Mixed Background)
- Asian or Asian British (Indian, Pakistan, Bangladeshi, any other Asian background)
- Black or Black British (Caribbean, African, or any other Black Background)
- Chinese
- Any other ethnic group
- Prefer not to say

Please specify:

____

____

6 **Some people care for more than one person. How many people do you look after?**

- 1 person
- 2 people
- 3 people
- More than 3

Please specify:

____

____

7 **What is your relationship to the person/s you provide care for?**

- Partner
- Parent
- Parent-in-Law
- Grandparent
- Child (Under 18)
- Adult child (Over 18)
- Sibling
- Friend
- Neighbour
- Other

Please specify:

8 **The person(s) I care for has care and support needs as a result of? (Please check all that apply)**

- Physical disability or mobility problems
- Learning Disability
- Autistic Spectrum Condition
- Communication Problems
- Mental Health (including anxiety and depression)
- Long-term or serious illness or condition
- Frailty
- Drug or alcohol problems
- Sensory difficulties (e.g. sight or hearing problems)
- Dementia or memory problems

9 **How old is the person(s) you care for? (Please check all that apply)**

- Under 18 years
- 19-25
- 26-34
- 35-44
- 45-54
- 55-64
- 65-74
- 75-84
- 85-94
- 95 years +

Theme 1 – Identification of Carers

Identifying and recognising Carers and ensuring they can access the right support is a continuing priority, alongside improving Carers recognition of their role.

10 **Have you had a conversation with an NHS, social care or third sector professional e.g a GP, nurse or social worker about what to do if the condition of the person you care for deteriorates or you are no longer able or willing to provide care for them?**

- Yes
- No

For many people it takes time to recognise that they have taken on a caring role and that support is available to them as a 'carer'.

11 **Many people who take on caring responsibilities do not recognise themselves as 'carers'. How long did it take for you to realise that you had taken on a caring role?**

- Immediately
- Six months or less
- 7-12 months
- 1-2 years
- 3-4 years
- 5-7 years
- 8-10 years
- 11-15 years
- 16 years or more

12 **Do you feel you missed out on support as a result of not recognising you were a carer?**

- Yes, I missed out on financial support
- Yes, I missed out on practical support (e.g. getting a break, carer support groups)
- No
- Don't know

13 **What impact did missing out on support have? Please tick all that apply.**

- It impacted negatively on my finances
- I had to give up work to care
- My physical health suffered
- I suffered from stress or anxiety
- It put a strain on my relationship with the person I care for
- It put a strain on my relationships with other people
- In another way

14 **Please provide more details:**

Support for caring

We'd like to hear more about the kinds of support that carers are getting...

15 **Do you receive or buy any practical support with caring? Please tick all that apply.**

- Equipment in the home of the person I care for (like hoists, grab rails or easy-grip handles on taps)
- Technology like alarms, sensors or remote monitoring to help with caring
- Practical support from care workers coming in to help
- Use of a day centre for older/disabled people
- Help managing or co-ordinating care
- A break for me from caring
- Specialist childcare for a disabled child
- Help with other household chores (like shopping or cleaning)
- 'Live in' support (someone who is paid to live with us/the disabled/older person I care for to provide care and support)
- Help from family or friends
- Occasional use of a care home
- Occasional use of a hospice
- The person I care for lives in a care home
- None

- Extra childcare for children who are not disabled (which helps me to care for my other loved ones)
- A Motability vehicle
- Other

Please specify:

____

____

Using technology to make caring easier

Technology can provide reassurance for carers and independence for those we're looking after.
From simple mobile apps to complex sensor systems, there are many products already available to help make life a little easier.

16 **Do you or the person/people you care for use any of the following technology to support care and caring? Please tick any that apply.**

- Yes, internet as a source of information
- Yes, internet as a form of communication or online support
- Yes, environmental monitoring such as heating and lighting control, door video systems, smart appliances
- Yes, remote monitoring and alerts such as motion sensors, fall detectors, personal alarm, GPS trackers
- Yes, vital signs monitoring such as blood pressure monitor, blood glucose monitor, heart rate monitor
- Yes, remote health care such as online GP appointments, repeat prescriptions, online video consultations, online mental health
- Yes, apps such as for pain management, mood management, care co-ordination
- Yes, medication management tools such as medication dispensers or medication reminders
- No, we don't use technology to support caring
- I don't know

17 **Please tell us anything else you think is important about theme 1 – identification of carers. Is there anything else health, social care or third sector partners could do to identify and recognise carers who need support?**

Younger carers: How can we make sure that you, as a young carer, feel able to come to us for any help and support you need? i.e. someone to talk to, to listen; an easy way to contact someone (FB, twitter social media)

Theme 2 – Supporting Life Alongside Caring

Providing opportunities for Carers to have reasonable breaks from their caring role to enable them to maintain capacity to care, and to have a life beyond caring is a key priority area.

18 **In addition to your caring role, please tell us which of the following also applies:**

- In Education
- Employed full-time
- Employed part-time (working 30 hours or less)
- Self-employed full-time
- Self-employed part time
- Not in paid work
- Voluntary Work
- Retired
- Other (please specify)

Please specify:

19 **During the last 6 months, thinking about being able to take a break from your caring responsibilities, which of the following statements best describes your situation?**

- I have as much time free of my caring responsibilities as I like
- I have some time free from my caring responsibilities but not enough
- I do not have any time free from my caring responsibilities

20 **Please provide any further comments:**

21 **Do you feel that caring has had an impact on your physical health and mental well-being?**

- Yes, I feel that caring has had a positive impact
- Yes, I feel that caring has had a negative impact
- No
- Unsure

22 **Please provide any further comments:**

23 **Please tell us anything else you think is important about Theme 2 – Supporting Life Alongside Caring? What would help you to better balance your caring role?**

Younger carers: What could we do to help so that you can have more time to the things that matter to you? i.e. Some company for cared for; personal care etc

Theme 3 - Information, Advice and Assistance for Carers

Effective Information, Advice and Assistance is important in supporting carers in their vital role and continues to be a priority for action.

24 **Have you seen any information produced by your local authority, health board or third sector organisations that would help you in your role as a carer? This information could be online, a leaflet or through media (e.g. social media)**

- No, I have not seen any information
- I am not sure if I have seen any information
- Yes, I have seen information and in my opinion it was very useful
- Yes, I have seen information and in my opinion it was useful
- Yes, I have seen information and in my opinion it was not useful

25 **Please tell us what information you found most useful?**

26 **Have you accessed Carer Information Services (CIS) for Information, Advice, or Assistance (IAA) in the last 12 months? Please tick all that apply.**

- Yes, I have telephoned CIS
- Yes, I have emailed CIS
- Yes, directly with the Carers Scotland or Carers Wales Office or through the Carers NI Advice line
- Yes, through the online forum
- Yes, I have been in touch with one of your volunteers
- Yes, through the pages or downloadable resources on the websites
- Yes, through printed information booklets or factsheets
- Yes, through one of the Facebook pages
- Yes, through one of the Twitter feeds
- Yes by using a mobile app,
- No
- Yes, other

Please specify:

____

27 **If yes, has the Information, Advice or Assistance you accessed helped you in any of the following ways? Please tick all that apply.**

- Be more knowledgeable about the practical support available and how to access it
- Be more knowledgeable about benefits and/or other financial help available
- Be more knowledgeable about my rights as a carer
- Helped me take action to get more practical support
- Helped me take action to increase the financial help I/the person I care for receive e.g. through benefits
- Helped me take action to exercise my rights as a carer
- Helped me feel less anxious
- Helped me feel more able to manage caring
- My physical health has improved
- My mental and/or emotional health has improved
- My relationships are better
- Not sure yet
- It has not helped me
- In another way

Please specify:

____

28 **Have you had a carer's assessment or a review of your assessment in the last 12 months?**

- No
- I have been referred and I am waiting for my assessment/ review
- Yes and I waited less than 6 months after requesting/being referred for it
- Yes but I waited more than 6 months after requesting/being referred for it

Your Assessment

29 **To what extent do you feel that the assessment process and subsequent consideration of the care and support needs of you and the person you care for sufficiently looked at the following areas?**

	This was not properly considered in my assessment or in support I receive	This received some but insufficient consideration	This was thoroughly considered and reflected in the support I receive
Your ability and willingness to provide care	▪	▪	▪

The support you need to look after your own mental and physical health alongside caring	▪	▪	▪
The support you need to provide care for others (i.e. a non-disabled child or someone else with care or support needs)	▪	▪	▪
The support you need to juggle care with work or return to work	▪	▪	▪
The support you need to juggle care with training or education	▪	▪	▪
Your ability to maintain relationships with family and friends	▪	▪	▪
The need to have regular breaks from caring	▪	▪	▪
Your ability to have time to yourself	▪	▪	▪
The suitability of your housing for continuing your caring role	▪	▪	▪
What needs to be put in place for the person you support in case of an emergency	▪	▪	▪
If relevant, the support you need as the person you care for or you transition from children's to adult services	▪	▪	▪
Other	▪	▪	▪

Please specify

____

____

30 **Please tell us anything else you think is important about theme 3 – Providing Information, Advice and Assistance. What information would you find most helpful, and how would you prefer to access advice and assistance?**

Younger carers: What do you need to know that may help you and the person you care for? i.e. may not know what they need to know!

____

____

31 **Is there anything else you would like to tell us? Are there any additional priorities or support you would like to see being included in the regional strategy?**

Younger carers: Is there anything else you would like to tell us?

Coronavirus Pandemic

32 **Do you have any suggestions about how best to support unpaid Carers during the Coronavirus Pandemic?**

Younger carers: What can we do to help you now? i.e. during (and maybe after the lockdown)

If you would like to share your views and experiences of unpaid carers please join the Siarad Iechyd/Talking Health involvement scheme and have a say in how local health and social care services are developed and delivered by completing the online application form at www.talkinghealth.wales.nhs.uk/applicationform or telephone 01554 899 056 for an application form.

If you would like any information, advice or support, please contact your local Carers Information Service:

Carmarthenshire Tel: 0300 0200 002 Email: info@carmarthenshirecarers.org.uk

Ceredigion Tel: 01970 633564 Email: carersunit@ceredigion.gov.uk

Pembrokeshire Tel: 01437 611002 Email: PCISS@crossroadsmww.org.uk

Thank you for taking the time to complete this survey

Appendix 2 - List of networks used in survey dissemination.

Aberporth FS Reference Group
Action for Children
Age Cymru
Age Cymru Ceredigion
Age Cymru Sir Gar
All Wales Forum
Alzheimer's Society
Aman Tawe Partnership
Barnardos
Blesma
Borth Family Centre
British Legion
Brynteg Medical Practice
CAB Ceredigion
CAIS
Cardigan Integrated Children's Campus
Care and Repair Carmarthenshire
Care Forum Wales
Carers Trust / Crossroads Sir Gar
Carmarthenshire Association of Voluntary Services
Carmarthenshire Carers Forum
Carmarthenshire County Council
Carmarthenshire Hafal
Carmarthenshire People First
Carmarthenshire Youth and Children's Association
CATCH UP (Carers Trust)
Ceredigion Association of Voluntary Organisations
Ceredigion Carers Alliance (CCA)
Ceredigion Citizens Advice Bureau
Ceredigion County Council
Ceredigion Older Adult Mental Health Team
Ceredigion Parenting and Family Support Group
Children's Commissioner for Wales
Children's Rights Unit
Coleg Sir Gar
Community Choice and inclusion
Credu Cymru
Crossroads Mid and West Wales
CRT/ART South Ceredigion team

Department of Work and Pensions
Drug and alcohol services
Dyfed Powys Police
Ethnic Youth Support Team
Flying Start Team and Child Poverty Group
Gofalwyr Ceredigion Carers
Gofalwyr Ceredigion Cymru
Hafal Cymru
HDUHB Macmillan Information & Support Service
Help for Heroes
Hywel Dda University Health Board
Investors in Carers settings, including:
Jigso
Lampeter Family Centre
Links Mental Health Support Llanelli
Llanarth FS Reference Group
Llandysul Integrated Children's Campus
Milford Youth Matters
MIND Carmarthenshire
MIND Ceredigion
MIND Pembrokeshire
Ministry of Defence
Pembrokeshire Association of Voluntary Services
Pembrokeshire Carers Information Service
Pembrokeshire County Council Youth Services
Pembrokeshire People First
Pembrokeshire Youth Forum
Penparcau Integrated Children's Campus
Plant Dewi
Poppy Factory
RAY Family Centre
Red Cross
Siarad Iechyd
SRG
SSAFA
Stroke Association
Tanyard Project Pembroke
Tregaron Family Centre
University of Wales Trinity Saint David
Welsh Ambulance Service Trust
West Wales Action for Mental Health
West Wales Domestic Abuse Service
Woody's Lode: Armed Forces Support
Ysgol Bro Dinefwr