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Title: An Environmental Scan of Online Resources for Informal Family Caregivers of ICU Survivors

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None

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Abstract (200 words)

Purpose

To collate a comprehensive repository of online resources for family caregivers of intensive care survivors to inform a recovery website and digital peer support programme.

Materials and methods

To identify resources, we conducted an environmental scan using processes recommended by the Canadian Agency for Drugs and Technologies in Health and guided by clinical experts, former patients, and family members. We searched internet sources, professional society websites, social media, and contacted our professional networks.

Results

Through expert consultation we identified 16 information categories and found 301 online resources. Five categories with the most resources were: how to look after yourself/recognise anxiety or post-traumatic stress/getting mental health support (n=63); information specific to conditions necessitating ICU admission (n=49); multiple category resources (n=46); symptoms of post-intensive care syndrome (n=44); stories of lived experience (n=23). Five categories with the least resources were physical, emotional and cognitive symptoms of post-intensive care syndrome-family (n=1); interacting with primary care (n=2); medical deterioration (how to recognise/what to do) (n=2); driving and accessing the community (n=3); end-of-life and bereavement (n=5). Of these resources, we included 45 on our recovery website.

Conclusion

This environmental scan identifies multiple resources addressing informational needs of family caregivers and highlights areas for resource development.

Keywords

Caregivers; family; critical care; recovery; resources; environmental scan

Introduction

Approximately 80% of adults admitted to an intensive care unit (ICU) survive and are discharged home [1]. Many will experience new or worsening physical, mental, or cognitive problems known as post-intensive care syndrome (PICS) [2]. Up to a quarter of ICU survivors require assistance with activities of daily living (e.g., dressing, feeding and toileting) from family members in the home as well as help with rehabilitation activities up to one year after hospital discharge. The repercussions of surviving an ICU admission also extend socially and economically. A recent systematic review on return to work after critical illness found previously employed ICU survivors had a return-to-work prevalence of 64% at six months, 60% at one year, and 68% after five years. Despite returning to work, most survivors experienced decreased income and increased receipt of state financial support [3].

Family members of patients recently discharged from ICU also experience post-intensive care syndrome (termed post-intensive care syndrome-family (PICS-F)) [4-6]. Psychological morbidities associated with PICS-F include anxiety, depression, post-traumatic stress disorder (PTSD), and complicated grief [7, 8]. Moreover, most of the assistance or care needed in the home by ICU survivors is provided by informal family caregivers. Care needs can be substantial, with some individuals requiring over 50 hours each week, described as 'never-ending care' [4, 7]. This substantial burden on informal family caregivers can result in sleep disorders, nightmares, distress, and exhaustion [8]. Family members describe a cycle of worsening physical health, increasing mental distress, social withdrawal, and family crisis [4]. Family members may also have to undergo major adjustments to provide care in the home, including leaving employment and re-mortgaging or selling their homes [7].

Despite the documented repercussions of an ICU admission on both patients and family members, informal family caregivers continue to receive limited information about recovery from critical illness, both in ICU and following hospital discharge [9]. This is despite ICU survivors and family members expressing the need for this information. Provision of online resources has been highlighted as a successful support initiative by caregivers of ICU survivors [10]. Furthermore internet-based resources are now the predominant source of health-related information used by the public [11]. Therefore ensuring access to appropriate resources addressing identified needs on a range of topics relevant to supporting patient recovery and family member wellbeing is important.

Our overall aim was to collate a comprehensive repository of online resources on subjects important to the needs of informal family caregivers of ICU survivors once discharged from hospital as identified through consultation with clinical experts, former patients, and family members.

Materials and methods

Study design

We conducted an environmental scan using methods outlined by the Canadian Agency for Drugs and Technologies in Health (CADTH) environmental scan [12]. We selected this method as it is designed to provide an overview of current practices and the use of technologies to highlight existing or projected healthcare issues or issues associated with specific technology introduction, in our case, a website providing informational support for ICU survivors and family members. Following topic identification, this method consists of four phases: refinement, research, external review, and delivery.

Refinement phase: Consultation meetings

To identify relevant information categories to guide our environmental scan, we conducted two consultation meetings, one with an Expert Advisory Group (EAG) and one with a project-specific Patient and Public Involvement (PPI) group.

We held consultation meetings in January 2022 via Microsoft Teams facilitated by two project team members and recorded with the participants' consent. The meetings were transcribed using the auto-transcription feature of Microsoft Teams and reviewed for accuracy. Using a pre-prepared question list (see Supplementary Material), we asked the EAG to identify information subjects important to informal family caregivers by considering questions they were frequently asked and what they felt family members needed to know. We also asked them to identify existing resources and those that needed development. We asked our PPI group what information and resources they thought should be available to family members when a patient is discharged from hospital following an ICU admission. We also explored what type of information they had received or accessed and found most useful.

Research phase: search for online resources

Online resource eligibility criteria

The environmental scan inclusion criteria comprised: (1) a website, webpage, PDF document or similar (online resource) available via a hyperlink targeted to the needs of adult informal family caregivers to support adult ICU survivors during recovery; (2) an online resource relating to an information category identified through our expert consultation; (3) available in English; (4) suitable for a UK audience (either generic or UK-specific); and (5) free to access.

Exclusion criteria comprised: (1) resources targeted to paediatric patients, relatives, or paediatric-specific conditions; (2) inpatient ICU information; (3) resources specific to a regional (county) population within the UK (4) research publications; (5) information directed to healthcare professionals; (6) websites listed as advertising; and (7) Wikipedia.

Search resources and methods

Social media

We used our Life Lines Twitter account (https://twitter.com/LifeLines_ICU) to seek information from followers on relevant online resources. Our Twitter account has 2,480 followers representing clinicians, researchers, and members of the public with an interest in intensive care.

Professional networks

We e-mailed health professionals and experts in our professional networks from the fields of ICU and ICU follow-up to request online resources provided to informal family caregivers. In addition, we contacted health professionals representing the clinical multidisciplinary team from six UK hospitals with dedicated ICU recovery services, (University Hospital of Wales, University Hospitals Plymouth, University Hospitals Coventry and Warwickshire, Guys and St Thomas' Hospital, King's College Hospital, and Barts Health NHS Trust). We also contacted experts from the Intensive Care Society and ICUSteps, the UK's leading charity for ICU survivors.

Professional Society Websites

We reviewed the following professional society websites for online resources; UK Intensive Care Society (https://ics.ac.uk/), Faculty of Intensive Care Medicine (https://ics.ac.uk/), American Thoracic Society (https://www.ficm.ac.uk/), American Thoracic Society (https://www.thoracic.org/), Society of Critical Care Medicine (https://www.sccm.org/), and European Society of Intensive Care Medicine (https://www.esicm.org/).

Internet Searches

We conducted internet searches using the Google search engine. We determined search terms by identifying keywords associated with the information categories identified during our consultation meetings. On entering a search term, we opened the first fifty results listed (five pages) and screened the content against our eligibility criteria. Only working links were opened, and duplicate online resources were disregarded. A complete list of the search terms and an example search using the search term "family support ICU" is provided in the Supplementary Material.

The search of professional society websites and internet searches was undertaken between December 2022 and January 2023. All identified online resources were collated on Microsoft Excel. One team member (EF) labelled each website an "ICU-specific online resource" or "an online resource with ICU applicable content". Online resources were considered 'ICU-specific' if they contained information on ICU, critical illness, experiences of ICU patients or family caregivers, and critical illness recovery, for example, the ICU Steps website (https://icusteps.org/). Websites considered "ICU-specific" were searched for hyperlinks to further online resources. An online resource was considered to have "ICU applicable content" if the information contained was related to an informational category identified by our consultation meetings. An example of a website with ICU-applicable content was the British Red Cross website (https://www.redcross.org.uk/get-help) that provides information on mobility and cost of living support. Websites with "ICU applicable content "were not searched further for additional hyperlinks.

Online resource categorisation and review

We used an iterative process to categorising online resources. One team member (EF) initially categorised each online resource as to the information category the content or purpose primarily fulfilled; for example, the homepage for the Carers Trust (https://carers.org/) fulfilled the category "physical strain and caregiver support". A new information category was made if the content fulfilled our eligibility criteria but did not fit into an information category identified during our consultation meetings. The categorised list of online resources was then assessed by a second team member (SS) to confirm inclusion and fit with the information category. Conflicts regarding inclusion and/or categorisation

were resolved with discussion between the two reviewers (EF, SS) and confirmed by a third reviewer (LR).

External review phase

To inform selection of resources for our local critical care recovery website hosted by Guy's & St Thomas' NHS Foundation Trust in London UK a third team member (LA) further reviewed the list for website inclusion, applying the following criteria:

- 1. Resources relevant to London boroughs.
- 2. Avoidance of PDF-only resources where possible to address accessibility issues.
- 3. Inclusion of only common ICU-related conditions to make the website more easily navigable. For example, online resources describing ICU-related anxiety were included, but not those relating to generalised anxiety disorder. It was assumed that people looking for condition-specific information (e.g., asthma, head injury, COVID-19) would find this elsewhere.

Delivery phase

We planned to make the results of our environmental scan publicly available via a data repository and a critical care recovery website

Results

Advisory group participants

Our four EAG members were experts in ICU recovery and/or peer support and comprised two Nurse Consultants specialising in recovery following critical illness; one peer support expert; and one dietician specialising in critical illness and recovery. Our PPI group comprised one former ICU patient and three family members of ICU survivors. Membership of both was ethnically diverse, including Black Afro-Caribbean, White British, and Other ethnicities. All members of both groups were female.

Information category identification

Our consultation meetings with our advisory groups identified 14 potential information categories: 10 from the EAG group and 4 from the PPI group (see Table 1). Following team discussion, we combined categories due to topic overlap/similarity. This included merging "social and welfare benefits" with "financial support", as well as "how to look after yourself/recognise anxiety or post-traumatic stress, and getting support" with "mental health

support". The category "what to expect from your relative including signs of deterioration" was changed into the two categories of "what to expect from your relative and practicalities of being at home" and "medical deterioration (how to recognise/what to do)". This process resulted in 16 informational categories

Search results

Our environmental scan identified 325 online resources: 23 from our consultation meetings; 19 from social media; 205 from our professional networks; 13 from professional society websites; and 81 from internet searches. On independent review, 14 online resources were excluded, predominantly due to the content being specific to COVID-19 lockdown or furlough. Disagreement between reviewers occurred for 48 online resources. After discussion of the 48 conflicts, 10 were excluded and the remainder included. The main reason for exclusion was that the content was more suitable for patients and their families at the time of ICU admission rather than in recovery at home

In total, 301 online resources were included and categorised. A flow diagram of our review processes is shown in **Error! Reference source not found.** The final information categories and the number of online resources identified per category is provided in Table 2. A full list of the 301 online resources according to information category, is provided in the Supplementary Material. This comprehensive online resource repository is now publicly available to family caregivers, patients, and clinicians via a data repository https://data.mendeley.com/datasets/42mzcbtk3h/1, Of the 301 online resources identified, 45 were selected for inclusion on our critical care recovery website https://gstt.criticalcarerecovery.com. This website has been adapted from a website originally developed for Scotland (https://www.criticalcarerecovery.com).

Discussion

Through our expert consultation guided environmental scan, our work provides an understanding of the categories of informational needs of family caregivers of ICU survivors and has identified 301 online resources addressing these categories. This is now freely available as an online repository and via a critical care recovery website. Although we identified online resources within all information categories, we discovered a paucity in several categories, including: "physical, emotional and cognitive symptoms of PICS-F",

"interacting with primary care", and "medical deterioration (how to recognise/what to do)". Importantly, multiple resources were identified that support mental health of both patients and family members. Interestingly, fewer resources were identified that focused on physical health and burden of family caregivers or practical guidance on how to manage the physical issues experienced by their relative recovering from critical illness.

We identified only one resource (YouTube video) specifically addressing PICS-F but 44 resources relating to PICS. This may reflect greater recognition of the physical, cognitive, and emotional consequences of critical illness for patients as opposed to their family caregivers. We also found few resources directly addressing family caregiver physical strain, the need for support and ways for caregivers to receive support. We did however identify multiple resources addressing emotional and psychological concerns. Psychological morbidity of family caregivers is prevalent and persistent. One longitudinal study found that 25% of family caregivers reported symptoms of PTSD at three months and 24% at one year [13]. Another study found 30% of family caregivers reported symptoms of PTSD 90 days after their relative developed chronic critical illness [14]. The reported prevalence of anxiety ranges from 42% to 80% and depression from 16% to 90% during the ICU or hospital stay. These symptoms persist with prevalence rates six months after ICU discharge of 15% to 24% for anxiety, 5% to 36% for depression, and 35% to 57% for PTSD [8]. It is, therefore, of utmost importance that family caregivers are made aware of the possible consequences of caregiving and provided with accessible informational resources and support.

We found only two online resources for the "interacting with primary care" information category. This is surprising given that primary care is the key care provider for ICU survivors and family members following hospital discharge. The lack of general practitioner knowledge about PICS and PICS-F enhances the need for informational resources on interacting with primary care so that the issues experienced by ICU survivors and family caregivers can be addressed appropriately [15]. One survey of general practitioners (GPs) based in the Netherlands found that 57% of responders were unfamiliar with the terminology and concepts relating to "PICS" and "PICS-F" [16]. In the UK, a survey of GPs found over 60% of responders were unaware of the ICU follow-up services provided by their local hospitals, with an expressed need for information about critical illness recovery [15]. Therefore, developing online resources to bridge this informational gap is imperative.

We identified only two online resources in the "medical deterioration (how to recognise/what to do)" category. This included the UK National Health Service (NHS) 111 online resource and a video called "3 soft signs of deterioration" on YouTube. A recent systematic review found that hospital readmission is common in this patient group with17% readmitted at 30 days; 31% at 90 days; 30% at six months; and 53% at one year [17]. Therefore better information on the signs of deterioration and when to call for help in a timely manner may ensure timely access to appropriate support and health services, which in turn may reduce or avoid readmission to hospital. We therefore recommended this as a key and pressing area for resource development preferably using co-design methods to ensure resources are tailored to the needs of family caregivers.

Strengths of our work include expert and end-user consultation to establish key information categories and the use of rigorous environmental scan methodology. Our work has limitations. Though ethnically diverse, our EAG and PPI group members were all female. This may have shaped the views and opinions shared. We limited our Google search to the first 50 results relating to our search terms. This may have missed some relevant resources. For pragmatic reasons, we sought only resources in English as they needed to be evaluated by our team. Without translation, this limits accessibility to non-English speaking family members. However, our publicly accessible critical care recovery website has an inbuilt translation function enabling the translation of resources into over 50 languages. Given our objectives, we sought only online resources applicable to the UK population with those included on the website bespoke to the needs of our local population. To address this limitation, we also host the full environmental scan on our online repository. Lastly, information on topic categories may not have been found if embedded within resources not linked to our specific search terms.

Conclusion

Our environmental scan has identified a substantial number of online resources relevant to the informational needs of family caregivers of ICU survivors, forming a comprehensive information repository. Many of these online resources focused on aspects of caregiver mental health or symptoms experienced by the ICU survivor. Fewer focused on the practical and physical issues family caregivers frequently face, specifically how to interact with primary care, recognise medical deterioration, and how to access help. Our work highlights a need for further resource development to address these gaps in informational resources.

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Table 1 Information categories.

	Original information categories	Final information categories
Information	What to expect from your relative including signs of	What to expect from your relative and practicalities of being
categories from	deterioration	at home
Patient and Public	Practicalities of being at home	
Involvement Group	Nuggets of useful information	Resources spanning various categories
	How to look after yourself/recognise anxiety or	How to look after yourself/recognise anxiety or post-traumatic
	posttraumatic stress, and getting support	stress, and getting mental health support
Information	Mental health support	stress, and getting mental health support
categories from	Symptoms of PICS-F	Physical, emotional and cognitive symptoms of post-intensive
Expert Advisory	Symptoms of Fies F	care syndrome-family
Group	Social and welfare benefits	Social/welfare benefits and financial support (including care
	Financial support	and return to work)
	Access to equipment and home adaptations	Access to equipment and home adaptations
	Physical caregiver strain	Physical strain and caregiver support
	Interacting with primary care	Interacting with primary care
	Medical deterioration	Medical deterioration (how to recognise/what to do)
	Cognitive difficulties	Symptoms of post-intensive care syndrome
	Pain management	
Additional	Post Intensive Care Syndrome (general)	
information	Eating and nutrition	
categories	Sleep	
	Flashbacks/ hallucinations	
	Fatigue	
	Breathing related (shortness of breath, cough, and	
	secretion clearance)	

Smell change or loss	
Hearing change or loss	
Voice change or loss	
Driving and accessing the community	Driving and accessing the community
End-of-life and bereavement	End-of-life and bereavement
Social networks	Social networks
Physiotherapy, exercise, and activities for ICU survivors	Physiotherapy, exercise, and activities for ICU survivors
Condition specific information	Information specific to conditions necessitating an ICU
COVID-19 specific (including long-COVID)	admission
Stories of lived experience	Stories of lived experience

The 'Original information categories' were identified by consultation meetings with our project-specific expert advisory and patient and public involvement groups. The project team developed these categories into the 'Final information categories' listed.

Table 2 Final information categories resources

Category	Number of
	resources
Physical, emotional and cognitive symptoms of PICS-F	1
Interacting with primary care	2
Medical deterioration (how to recognise/what to do)	2
Driving and accessing the community	3
End-of-life and bereavement	5
Physical strain and caregiver support	6
What to expect from your relative and practicalities of being at home	7
Access to equipment and home adaptations	7
Social networks	7
Physiotherapy, exercise, and activities for ICU survivors	15
Social/welfare benefits and financial support (including care and return to work)	21
Stories of lived experience	23
Symptoms of PICS	44
Information specific to conditions necessitating an ICU admission (i.e., sepsis)	49
How to look after yourself/recognise anxiety or post-traumatic stress, and getting mental health support	63
Multiple category resources	46

Consultation meeting questions

These questions were prepared by one member of the project team (SS) ahead of the consultation meetings with the Expert Advisory Group (EAG) and the Patient and Public Involvement (PPI) group.

Questions for the EAG:

- 1) What resources do you use to support families during/after their relatives ICU stay?
- 2) What resources are you aware of, to support families during/after a relatives ICU stay?
- 3) Where do you direct families to get support for their physical and emotional well-being?
- 4) Are these formal or informal resources (e.g. hospital information, social media (facebook/twitter/Instagram), GP surgeries, apps, charity websites, other websites, blogs)?
- 5) If you had a 'wish list' of resources you could offer families to support their physical and emotional wellbeing, during and after their relatives ICU stay, what would be on it?
- 6) What resources do you think family members need?

Questions for PPI group:

- 1) What resources have you used to get support during/after you relatives ICU stay?
- 2) What resources are you aware of, to support families during/after a relatives ICU stay?
- 3) Where do you look to get support for your physical and emotional well-being?
- 4) Are these formal or informal resources (e.g. hospital information, social media (facebook/twitter/Instagram), GP surgeries, apps, charity websites, other websites, blogs)?
- 5) If you had a 'wish list' of resources you could find to support your physical and emotional wellbeing, during and after your relatives ICU stay, what would be on it?
- 6) What resources do you think you and other family members need?

Professional society websites searched

UK Intensive Care Society (https://ics.ac.uk/)
Faculty of Intensive Care Medicine (https://www.ficm.ac.uk/)
American Thoracic Society (https://www.ficm.ac.uk/)
Society of Critical Care Medicine (https://www.sccm.org/)
European Society of Intensive Care Medicine (https://www.esicm.org/).

Search terms

Search terms were determined by identifying keywords associated with the information categories identified during our consultation meetings.

- Family support ICU
- Family support intensive care
- Practical family support intensive care
- Carer support
- Anxiety family intensive care
- Depression family intensive care
- Posttraumatic stress disorder family intensive care
- Mental health support family intensive care
- Post intensive care syndrome family
- PICS-F
- Social welfare financial support
- Hospital discharge equipment
- Hospital discharge home adaptations
- Cognition after intensive care
- GP after intensive care
- Primary care after intensive care
- Pain after intensive care
- Deteriorating at home after intensive care
- Medical deterioration at home

Example Search

An example search carried out on the Google search engine using the search term "family support ICU". All results are listed excluding results listed as an "Ad".

- 1. https://healthtalk.org/intensive-care-experiences-family-friends/sources-of-support-in-icu
- 2. https://icusteps.org/information/guide-to-intensive-care/for-relatives
- 3. https://icusteps.org/
- 4. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6452792/
- 5. https://www.apaservices.org/practice/ce/expert/supporting-families-icu
- 6. https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-021-07095-8
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- 22. https://www.friendsofpicu.org.uk/what-we-do/child-and-family-support/
- 23. https://healthbeat.spectrumhealth.org/families-of-critically-ill-patients-need-extra-support-too/
- 24. https://ebn.bmj.com/content/23/1/15
- 25. https://www.atlantichealth.org/conditions-treatments/intensive-care/icu-resources.html
- 26. https://cardiffcriticalcare.co.uk/leaflet-information/
- 27. https://www.chelwest.nhs.uk/your-visit/patient-leaflets/icu/intensive-care-unit-icu-information-for-family-and-friends
- 28. https://www.sciencedirect.com/science/article/abs/pii/S0883944120307176
- 29. https://www.wsh.nhs.uk/CMS-Documents/Patient-leaflets/CriticalCareServices/Web-resources-to-support-relatives-and-patients-in-Critical-Care-Unit-002.pdf
- 30. https://healthmanagement.org/c/icu/news/six-icu-patient-and-family-info-resources
- 31. http://ferronfred.eu/ferron_fred/classe_anesthesie_-
 reanimation/Entrees/2010/3/30_articles_files/Supporting%20families%20in%20the%20ICU
 -
 - $\frac{\%20A\%20 descriptive\%20 correlational\%20 study\%20 of\%20 informational\%20 support,\%20 anxiety,\%20 and\%20 satisfaction\%20 with\%20 care.pdf$
- 32. https://nursinganswers.net/essays/family-support-programme-icu-patient-4590.php
- 33. https://caregiver.com/articles/surviving-ICU/
- 34. https://www.canadiancriticalcare.org/Patients-&-Families
- 35. https://www.nhs.uk/conditions/intensive-care/

- 36. https://www.rn.com/featured-stories/emotional-impact-on-icu-patients-and-families/
- 37. https://austinpublishinggroup.com/nursing-research-practice/fulltext/anrp-v6-id1044.pdf
- 38. https://www.uptodate.com/contents/communication-in-the-icu-holding-a-meeting-with-families-and-caregivers
- 39. https://media.gosh.nhs.uk/documents/When your child is in the Intensive Care Unit IC
 U.pdf
- 40. https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2781118
- **41.** https://mydoctor.kaiserpermanente.org/ncal/Images/Family%20Guide%20to%20ICU_tcm75 -854750.pdf
- 42. https://www.itmedicalteam.pl/articles/quality-of-life-and-family-support-in-critically-ill-patients-following-icu-discharge-106433.html
- 43. https://www.criticalcarerecovery.com/Search.aspx?tag=257
- **44.** https://www.jwatch.org/na54562/2022/02/24/structured-family-support-helps-mitigate-grief-after-death

Online resources identified by the environmental scan.

Each online resource is listed and described. The information category each online resource fulfils is indicated by an 'X'.

Link to online resource	Description	Informa	ation	category													
		What to expect from your relative and the practicalities of being at home	Multiple category resources	How to look after yourself/recognise anxiety or posttraumatic stress disorder, and where to get mental health support	Physical, emotional and cognitive symptoms of post-intensive care syndrome-family	Social/welfare benefits and financial support (including care and return to work)	Access to equipment and home adaptations	Physical strain and carer support	How to interact with primary care	Medical deterioration (how to recognise/what to do)	Symptoms of post-intensive care syndrome	Driving and accessing the community	End-of-life and bereavement	Social networks	Physiotherapy, exercise and activities for ICU survivors	Information specific to conditions necessitating an ICU admission	Stories of lived experience
https://www.youtube.c om/watch?v=8cbw14lW LkY	Online video on intensive care unit acquired weakness	Х									3						

https://talkcpr.wales/	Information aimed to create awareness of what CPR and DNACPR advance decisions are, and to point people affected by life-limiting conditions towards	Х								
	resources and information. Aimed towards Welsh audience.									
https://www.networks. nhs.uk/nhs- networks/my- medication-passport	App to log medications to help people see and share them with health professionals	Х								
http://painconcern.org. uk/wp- content/uploads/2013/ 08/Managing-Medical- Appointments.pdf	Information on managing medical appointments. Aimed towards pain-related appointments, however, the information and advice are generalisable.	X								
https://www.ageuk.org. uk/information- advice/work- learning/technology- internet/video-calling/	Age UK guide on how to make a video call	X								

https://www.nhs.uk/medicines/ https://www.nhs.uk/using-the-nhs/about-the-nhs/how-to-get-your-medical-records/	NHS webpage on medicines arranged A-Z. Includes medication side effects NHS advice on accessing health records	X								
www.nhs.uk/oneyou	Information on how to improve physical and mental health and wellbeing.		Х							
https://www.icnarc.org /About/Patients- Relatives/For-Patients- Relatives	The Intensive Care National Audit & Research Centre webpage dedicated to patients and relatives. Links available through this page to other resources		X							
https://blog.thisinstitut e.cam.ac.uk/recovery- after-intensive-care	Short article about ICU and recovery		Х							
https://www.nhsaaa.ne t/media/1683/2017011 2intcare.pdf	Ayrshire & Arran after intensive care information		Х							
https://www.ouh.nhs.u k/patient- guide/leaflets/files/139 72Plife.pdf	Oxford University Hospital - life after discharge from intensive care booklet		Х							

Later II	Be distributed to the	Ι,	.,	1	1 1		— Т	1	1	1	1	1	
https://www.ruh.nhs.uk	Royal United Hospitals		X										
<pre>/patients//patient_infor</pre>	Bath - recovering after												
mation/CCM008_Recov	UCU booklet												
ering after a stay on													
ICU.pdf													
https://www.housinglin	Hospital 2 Home		X										
.org.uk/_assets/Resourc	services to assist the												
es/Housing/H2H/H2Hfa	return home of older												
ctsheet1.pdf	people												
https://www.wyccn.org	Critical care recovery]]	X										
/uploads/6/5/1/9/6519	manual from Central												
9375/cm13521_tig101.	Manchester University												
<u>12.pdf</u>	Hospitals												
https://www.sthk.nhs.u	Intensive care		X										
k/media/.leaflets/61fa8	rehabilitation manual												
b96e9a7b3.67645211.p	from St Helens and												
df	Knowsley Teaching												
	Hospitals												
http://flipbooks.leedsth	Critical care	,	x										
.nhs.uk/LN004315.pdf	rehabilitation												
	guidebook from The												
	Leeds Teaching												
	Hospitals												
https://www.chelwest.n	Recovery after ICU		X	İ									
hs.uk/your-	advice from Chelsea and												
visit/patient-	Westminster Hospital												
leaflets/icu/on-the-													
road-to-recovery													
https://www.youtube.c	Video on ICU and	,	x	1									
om/watch?v=F7cc21rPV	recovery	'											
Lk	recovery												
LIX													

https://www.uhs.nhs.uk /Media/UHS-website- 2019/Patientinformatio n/Visitinghospital/Reco vering-after-intensive- care-patient- information.pdf	ICU recovery information page from University Hospital Southampton.	X							
https://ics.ac.uk/about- icu/what-is-intensive- care.html	A short section on recovery after ICU from the Intensive Care Society	X							
https://www.plymouth hospitals.nhs.uk/downl oad.cfm?doc=docm93jij m4n8125.pdf&ver=112 88	Link to intensive care rehabilitation manual from Plymouth hospitals	×							
https://icusteps.org/	ICUSteps home page	X							
https://icusteps.org/ass ets/files/information- sheets/helping-you- recover.pdf	ICUSteps guide on recovery after ICU	×							
https://sepsistrust.org/ get- support/support/critical -illness-recovery/	Critical illness recovery information from The UK Sepsis Trust	Х							
https://www.scottishint ensivecare.org.uk/patie nts-families/sics- leaving-critical-care/	Scottish Intensive Care Society information on leaving critical care, including leaving hospital, coping at home, follow-up, and rehabilitation	X							

https://icusteps.org/inf ormation/guide-to- intensive-care/for- relatives	ICUSteps webpage for relatives.	X							
https://www.scottishint ensivecare.org.uk/patie nts-families/sics- patients-families-useful- resources/sics-patients- families-helpful- resources/	Scottish intensive care society website – multiple resources	X							
https://www.wficc.com /about- us/resources/patient- family-resources	World Confederation of Intensive and Critical Care webpage of patient and family links, available in different languages	X							
https://icusteps.org/inf ormation/guide-to- intensive- care/returning-home	ICU steps webpage on returning home after ICU	Х							
https://icusteps.org/home/patients	The ICUSteps homepage offers a range of topics relating to critical care and recovery	X							
https://icuunwrapped.c o.uk/	ICU unwrapped – offering a range of information on ICU,	Х							

	including a relative's									
	webpage									
https://healthandcarevi	NHS video library on	>	(
deos.uk/critical-care	Intensive Care									
https://invidious.fdn.fr/	ICUSteps Q&A on	>	(
watch?v=Re3p4VazZSU	fatigue, sleep, and									
https://www.nhs.uk/co	recovery tips NHS page on ICU with a)	,							
nditions/intensive-care/	short section about	'	`							
	recovery. Links available									
	on the webpage									
https://www.ageuk.org.	Age UK homepage	\								
uk/										
https://www.redcross.o	The Redcross website	>	(
rg.uk/get-help	provides information on									
	support after a hospital stay and mobility									
	support including hiring									
	a toilet aid or									
	wheelchair									
https://www.ageuk.org.	Health and wellbeing	>	(
uk/information-	advice including advice									
advice/health- wellbeing/	on leaving hospital from									
https://www.criticalcar	Age UK Critical Care Recovery)	<u>, </u>							
erecovery.com/	homepage – a collection		`							
	of information and links									
https://www.youtube.c	Discharge from ICU	>	(
om/watch?v=aMn8Yd2J	advice video from									
<u>Inl</u>	THRIVE (Society of									
	Critical Care Medicine).									

	Aimed towards an American audience, however, information is generalisable.								
https://www.criticalcar erecovery.com/x35/fam ilies_page/	The family support page of the critical care recovery website	X							
https://www.ics.ac.uk/l CS/COVID-19/COVID- 19 patient and relativ e/Patient and Relative Resources.aspx	Intensive Care Society webpage on ICU with a small section on recovery	X							
https://www.sccm.org/ MyICUCare/THRIVE	Society of Critical Care Medicine THRIVE initiative home page, providing resources and education for ICU survivors and their families related to post- intensive care syndrome	Х							
https://www.thoracic.o rg/patients/patient- resources/managing- the-icu- experience/after-the- icu-long-term-care-life- after-surviving-critical- illness.php	American Thoracic Society webpage on ICU and recovery.	X							

https://www.sccm.org/	Resource library	Х							
MylCUCare/Resource-	provided by the Society	^							
Library	of Critical Care Medicine								
Library	of Critical Care Medicine								
https://www.sccm.org/	Patient and family	Х							
MyICUCare/THRIVE/Pati	resources provided by								
ent-and-Family-	the Society of Critical								
Resources	Care Medicine								
https://www.thoracic.o	Patient fact sheets	Х							
rg/patients/patient-	arranged by topic,								
resources/topic-	including critical illness								
specific/	from the American								
	Thoracic Society								
https://www.ficm.ac.uk	Patient section from the	Х							
/index.php/for-patients	Faculty of Intensive								
	Care Medicine								
	containing multiple links								
	to information topics								
	·								
https://www.ficm.ac.uk	Faculty of Intensive	Х							
/index.php/forpatients/	Care Medicine website								
recovery-after-	section on recovery								
<u>intensive-care</u>	after ICU								
www.cc-sn.org	Homepage of critical	Х							
	care support network								
	which provides								
	opportunities to speak								
	with other patients and								
	families, exercise and								
	relaxation classes								

https://icusteps.org/ass ets/files/translations/en glish.pdf	ICUSteps intensive care guide	X								
https://ics.ac.uk/about- icu.html	Information about being in intensive care	X								
https://www.plymouth hospitals.nhs.uk/rehabl egend	#RehabLegend webpages from Plymouth Hospital with information and links to recovery information and videos	X								
https://www.beyondblu e.org.au/who-does-it- affect/multicultural- people/translated- mental-health- resources	General mental health information translated into other languages.		Х							
https://www.nhsinform .scot/illnesses-and- conditions/mental- health	NHS Scotland Self-help guides to mental health conditions. Targeted towards a Scottish audience		Х							
https://www.psycholog ytoday.com/us/blog/fo od- thought/201202/the- high-incidence-post- intensive-care-unit-icu- anxiety-and-depression	Information about post- ICU anxiety and depression from Psychology Today		Х							

https://www.mylifeafte ricu.com/adults-in- icu/post-traumatic- stress-disorder-ptsd/ https://icusteps.org/ass ets/files/information- sheets/worry-after- critical-Illness.pdf	Information from My Life After ICU – a website based in Australia and New Zealand ICUSteps guide on worry after ICU	X						
https://www.bacp.co.uk	Website to help find counsellors and psychotherapists in your area.	X						
https://www.samaritan s.org/	Samaritans provide confidential, unbiased emotional support, 24 hours a day, for people who feel distressed, desperate or suicidal	X						
https://www.criticalcar erecovery.com/Search.a spx?tag=100	Critical Care Recovery website results on anxiety	X						
https://www.ficm.ac.uk /forpatientsrecoveryaft erintensivecare/stress- and-anxiety-following-a- critical-care-admission	Intensive Care Medicine information on stress and anxiety following an ICU admission	Х						

https://www.criticalcar erecovery.com/Search.a spx?tag=100&page_id= 2#LinkList	Critical care recovery website information related to mental health support	X						
https://www.criticalcar erecovery.com/Search.a spx?tag=65	Critical care recovery website links related to depression	X						
https://www.icudeliriu m.org/patients-and- families/depression	Depression information specific to ICU patients and family members	Х						
https://www.mayoclinic .org/diseases- conditions/depression/i n-depth/depression/art- 20045943	Advice on supporting a family member or friend with depression	Х						
https://www.mind.org. uk/information- support/types-of- mental-health- problems/depression/fo r-friends-and-family/	Information on how to support those with depression from Mind	X						
https://www.nhs.uk/nh s-services/mental- health-services/	NHS website on mental health service - how to access NHS mental health services and where to get urgent help	Х						

https://www.verywellm ind.com/how- depression-can-impact- your-family-5097903	Information on the family impact of depression from Very Well Mind	X						
https://www.nhs.uk/ser vice-search/mental- health/find-a- psychological-therapies- service/	NHS website where you can search for local mental health services (IAPT). This is for people living in England.	Х						
http://assisttraumacare. org.uk/	Assist Trauma Care charity for support after trauma	Х						
https://www.ficm.ac.uk /forpatientsrecoveryaft erintensivecare/posttra umatic-stress-disorder- following-a-critical-care	Intensive Care Medicine information on posttraumatic stress disorder (PTSD) post ICU admission	X						
https://www.icudeliriu m.org/patients-and- families/ptsd	Information from ICUDelirium.org about PTSD after ICU	X						
https://www.nhs.uk/mental-health/conditions/post-traumatic-stress-disorder-ptsd/causes/	PTSD information and advice from the NHS	Х						
https://www.ptsduk.org /ptsd-from-being-in-an- intensive-care-unit/	PTSD advice and information from PTSD UK	X						

https://thrive.uk.com	Thrive is a mental well-being app which is available in partnership with charities, employers, insurers and other organisations. To access you will need a code from your organisation's HR or support team.	X						
https://www.cci.health. wa.gov.au/~/media/CCI /Mental-Health- Professionals/Anxiety/A nxietyInformation- Sheets/Anxiety- Information-Sheet09- Progressive-Muscle- Relaxation.pdf	Information sheet on progressive relaxation to help manage stress and anxiety	X						
https://www.feelinggoo d.app	Feeling Good offers Positive Mental Training audio programmes to lift your mood and recover from stress, anxiety, and depression by building resilience and developing positive feelings.	X						

https://www.headspace .com/	Guided meditations, animations, articles, and videos to manage stress and anxiety. The app is free for a trial period, however, a subscription is required after this elapses. Free content is available via the Headspace YouTube channel.		X						
https://www.liverpool.a c.uk/it/app- directory/catch-it/	The Catch It app offers strategies to help with anxiety and depression		X						
https://www.mypossibleself.com/	NHS app for mental well-being. Designed to aid anxiety, depression, and stress, and improve sleep. The app is free to download with in-app purchases to open more of the features.		X						
https://www.worry- tree.com	The worry tree app aims to help people take control and create an action plan for managing worry.		Х						

https://breathingspace.scot/	Breathing Space website. They offer free, confidential advice and support over the phone, to people who are feeling anxious, depressed, or low. This is for people living in Scotland.	X						
https://careclinic.io/the rapeutic-journaling/	Advice on therapeutic journaling and the CareClinic app which has an ejournaling function. The health app can also be used to document symptoms of various medical problems, organise selfcare, and give reminders for medication and doctor appointments.	X						
https://cove-app.com/	Cove app - supporting mental well-being by creating music	Х						
https://llttf.com/	Free online courses from Live Life to the Full to aid low mood and stress	X						
https://mindedforfamilies.org.uk/older-people	Mental health resources to help support older	X						

	people and those who care for them										
https://www.health-in-	Advice on mental			Х							
mind.org.uk/wellbeing_	wellbeing from Health										
resources/d139/	In Mind. This is aimed										
	towards a Scottish										
	audience however the										
	advice is applicable										
	outside of Scotland.										
https://www.mentalhea	Information about			Χ							
Ith.org.uk/explore-	anxiety from The										
mental-health/a-z-	Mental Health										
topics/anxiety	Foundation										
https://www.mentalhea	Help to manage money			Χ							
<u>Ithandmoneyadvice.org</u>	and mental health										
<u>/en/</u>	issues from the Mental										
	Health and Money										
	Advice website										
https://www.mind.org.	Mental health charity			Χ							
<u>uk/</u>	Mind homepage - for										
	mental health, well-										
	being advice and										
	support for yourself and										
	others										
https://www.mindful.or	6-minute mindfulness			Χ							
g/a-five-minute-	meditation video										
breathing-meditation/											
		ĺ	l l			1					

https://www.nhs.uk/mental-health/conditions/post-traumatic-stress-disorder-ptsd/treatment/	PTSD information and advice from the NHS	X						
https://www.nhs.uk/me ntal-health/feelings- symptoms- behaviours/feelings- and-symptoms/feeling- lonely/	Loneliness advice from the NHS	Х						
https://www.nhsinform .scot/healthy- living/mental- wellbeing/anger- management/how-to- control-your-anger	Advice on controlling your anger from NHS Inform Scotland	Х						
https://www.nhsinform .scot/healthy- living/mental- wellbeing/anxiety-and- panic/how-to-deal- with-panic-attacks	Advice on panic attacks from NHS Inform Scotland	Х						
https://www.nhsinform .scot/healthy- living/mental- wellbeing/five-steps-to- mental- wellbeing#overview	Advice from NHS Inform Scotland on the five steps for mental well being	Х						

11	·	1		1						
https://www.nhsinform	Low mood and		X							
.scot/healthy-	depression advice.									
<u>living/mental-</u>	Aimed towards Scottish									
wellbeing/low-mood-	audience from NHS									
and-depression/low-	Inform									
mood-and-depression										
https://www.nhsinform	Tips for coping with		X							
.scot/healthy-	depression. Aimed									
living/mental-	towards a Scottish									
wellbeing/low-mood-	audience									
and-depression/tips-										
for-coping-with-										
depression										
https://www.nhsinform	Breathing exercises for		Х							
.scot/healthy-	stress. Aimed towards a									
living/mental-	Scottish audience									
wellbeing/stress/breath										
ing-and-relaxation-										
exercises-for-stress										
https://www.nhsinform	Self-help guide on PTSD.		Х							
.scot/illnesses-and-	Aimed towards a									
conditions/mental-	Scottish audience.									
health/mental-health-										
self-help-guides/ptsd-										
and-cptsd-self-help-										
guide/										
https://www.psycholog	Critical illness, intensive		X							
ytools.com/assets/covid	care, and PTSD patient									
	guidance. Available in									
19/critical illness inten	Albanian, Arabic,									
sive care and ptsd en-	Bulgarian, English (GB),									
gb.pdf	English (US), French,									
	Greek, Italian, Polish,									

	Romanian, Russian, Spanish, Tagalog, Turkish and Vietnamese							
https://www.thecalmzo ne.net/what-we-stand- for	Help and services for those affected by suicide from The Calm Zone	Х						
https://www.wearewith you.org.uk/	We are with you charity - drug, alcohol and mental health advice and support. Aimed towards English and Scottish audience.	Х						
https://www.imalive.or	A website which provides links to international mental health helplines, hotlines and websites	Х						
https://www.sane.org.u k	A charity which provides emotional support for people with a mental illness and their carers	X						
https://www.cc- sn.org/ files/ugd/4a06e d_08ebb649c157495a8 4c1d1dbb6a3b55f.pdf	Self-help guide on panic	Х						

https://www.cc-	Self-help guide on PTSD	Х						
sn.org/_files/ugd/4a06e								
<u>d_0e962a3fdddf49029e</u>								
a68d08d384a343.pdf								
https://www.cc-	Self-help guide on anger	X						
sn.org/_files/ugd/4a06e								
<u>d_4a19400920ac4eeda</u>								
<u>5abeab2062d9796.pdf</u>								
https://www.cc-	Self-help guide on	X						
sn.org/ files/ugd/4a06e	compulsive behaviour							
d_5a5093e9eb3740f28b	'							
fe60847e699288.pdf								
https://www.cc-	Self-help guide on stress	X						
sn.org/ files/ugd/4a06e								
<u>d_ad5fd371ace94376b4</u>								
de82facdf253db.pdf								
https://www.nhsinform	Self-help guide on	Х						
.scot/illnesses-and-	anxiety							
conditions/mental-	,							
health/mental-health-								
self-help-								
guides/anxiety-self-								
<u>help-guide</u>								
https://www.nhsinform	Depression self-help	Х						
.scot/illnesses-and-	guide							
conditions/mental-								
health/mental-health-								
self-help-								
guides/depression-self-								
<u>help-guide</u>								

https://www.nhsinform .scot/illnesses-and- conditions/mental- health/mental-health- self-help-guides/social- anxiety-self-help-guide	Self-help guide to social anxiety		X								
https://www.youtube.c om/watch?v=0XCmCG6 sn3w&t=3s	Video on coping with flashbacks		Х								
https://goodthinking- strapi.s3.eu-west- 2.amazonaws.com/GT Trauma Workbook Fin al 8dada6a4eb.pdf	South London and Maudsley NHS advice on coping with trauma		Х								
https://www.youtube.c om/watch?v=MhdZGNa N6b4	YouTube video on PICS-F			Х							
https://www.citizensad vice.org.uk/	The Citizens Advice – advice on legal, money and other problems. Free, independent, and confidential.				Х						
https://www.redcross.o rg.uk/get-help/get- support-at-home	Information from the Red Cross about getting support at home as well as hiring equipment such as a wheelchair or toilet aid				Х						

https://www.citizensad vice.org.uk/debt-and- money/get-help-with- the-cost-of-living/	Citizens Advice webpage on gaining help with the cost of living, including benefits		X						
https://www.familysup portni.gov.uk/Support/ 31/financialwelfare- advice-for-families	Financial support advice for families, from the Northern Irish government website		Х						
https://www.gov.uk/uni versal-credit	UK Government information on Universal Credit - for those on a low income, those who can't work, or who are out of work		X						
https://www.nidirect.go v.uk/campaigns/finance -support	Financial Support Service advice for those in Northern Ireland.		Х						
https://www.gov.uk/br owse/benefits/help-for- carers	Government webpage on benefits and financial support for carers		Х						
https://www.acas.org.u k/	Online information with advice on workplace rights		X						
https://www.citizensad vice.org.uk/family/looki ng-after- people/managing- affairs-for-someone- else/	Information about managing affairs for another person when they are unwell from Citizens Advice		X						

https://www.citizensad vice.org.uk/work/sick- leave-and-sick- pay/how-to-get-sick- pay/	Online information about rights at work and sick pay from Citizens Advice			Х						
https://www.nhs.uk/co nditions/social-care- and-support- guide/money-work-and- benefits/benefits-if- you-are-over-state- pension-age/	NHS information about benefits you can receive if you are over state pension age, benefits, and attendance allowance			Х						
http://www.moneymatt ersweb.co.uk/	Money advice centre. Aimed towards Scottish audience however many tools are not region specific			Х						
https://england.shelter. org.uk/housing_advice# title-2	Housing advice from Shelter			Х						
https://www.moneyhel per.org.uk/en	Impartial and free financial advice, HM Government website			Х						
https://www.turn2us.or g.uk/	Turn2Us website - a national charity that helps people in financial hardship to gain access to benefits, charitable grants and support services, including the bereaved.			Х						

https://www.ageuk.org. uk/information- advice/money-legal/	Financial advice from Age UK. This includes information on benefits as well as legal matters, such as making a will and power of attorney		X					
www.ageuk.org.uk/info rmation-advice/care/	Age UK's main webpage for learning about arranging social care. This includes understanding the type of care required and financial advice on how care is paid for		Х					
https://sepsistrust.org/ wp- content/uploads/2020/ 06/Employer-Critical- Illness-Guide.pdf	Advice on returning to work after ICU from the Sepsis Trust		X					
https://www.nhs.uk/co nditions/social-care- and-support- guide/help-from-social- services-and- charities/getting-a- needs-assessment/	NHS website on having a needs assessment for equipment or changes to your home, practical help from a paid carer, access to day centres and moving to a care home		X					

	T				1 1	ı ı					
https://www.gov.uk/pip	Personal Independent			Х							1
	Payment advice from										1
	the UK government										
https://www.cc-	ICUSteps webinar			Х							
sn.org/bb-law-video	providing advice on										
	financial support and										
	benefits										1
https://www.aatgb.com	Information on a piece				Х						
/deliver-more-safe-	of equipment to assist										
hospital-discharges-re-	people to move up and										
use-equipment/	down the stairs - a stair										
	climber										Ì
https://www.uhcw.nhs.	Information leaflet on				Χ						
uk/download/clientfiles	equipment that is										
/files/Patient%20Inform	generally available to										
ation%20Leaflets/Clinic	patients on leaving										
al%20Support%20Servic	hospital to assist with										
es/Occupational%20The	activities of daily living										
rapy/118685 Acitivty o	and personal care										
f daily living equipme	needs, such as raised										
nt for discharge from	toilet seats, mobility										
hospital (2114) Feb 20	aids, and perching										
<u>19.pdf</u>	stools. This may be										
	helpful when speaking										1
	to local services about										
	equipment you think										
	might be helpful.										

https://www.independe ntage.org/get- advice/your-home-and- housing/home- adaptations/home- adaptations-deciding- what-you-need	Webpage from Independent Age with advice on home adaptations			X						
https://www.boots.com /health- pharmacy/livingaids	Boots webpage for purchasing small pieces of equipment, e.g., long-handled aids, 7-day pill boxes, urine bottles, and shampoo caps.			X						
https://www.careline.c o.uk/careline-alarm- guide/	Telecare services			Х						
https://www.nhs.uk/co nditions/social-care- and-support- guide/care-services- equipment-and-care- homes/walking-aids- wheelchairs-and- mobility-scooters/	NHS information on getting a mobility aid, wheelchair, or scooter. Including, information on the Red Cross			X						
www.motability.co.uk	Motability - powered mobility equipment, wheelchair or scooter			Х						
https://carers.org/	Carers Trust homepage - the largest provider of				Х					

1	l	1	1	I	i i	1	1	1	1 1	1	1	1	ı	ĺ
	support services for													
	carers in the UK.													
https://www.ageuk.org.	Information for carers						X							
uk/information-	from Age UK, including													
advice/care/helping-a-	how to juggle work and													
loved-one/	caring, advice for if your													
	role has changed, and													
	looking after yourself as													
	a carer													
https://www.carersuk.o	Carers UK homepage						Х							
rg/	with help and advice for													
	carers													
https://www.carersuk.o	Carer support and						X							
rg/help-and-advice/	advice from Carers UK,													
	including financial and													
	practical support, work,													
	and carer advice, as well													
	as help to take a break.													
https://www.nhs.uk/co	NHS information about						X							
nditions/social-care-	support and financial													
and-support-	benefits for carers													
guide/support-and-														
benefits-for-carers/														
https://www.nhs.uk/co	NHS advice on having a						X							
nditions/social-care-	carer assessment. The													
and-support-	assessment is to see													
guide/support-and-	what would make life													
benefits-for-	easier as a carer. This													
carers/carer-	may include manual													
assessments/	handling advice, local													
	support groups, and													
	gym memberships to													
	help relieve stress.													

https://www.criticalcar erecovery.com/x24i57/ your_gp.aspx	Advice from the critical care recovery website on visiting your GP					x					
https://www.criticalcar erecovery.com/x31i125 /when_should_i_go_to _my_gp.aspx	Further advice on speaking with your GP from the critical care recovery website				2	X					
https://www.youtube.c om/watch?v=7gMo13z3 BYI	NHS video about spotting medical deterioration - "soft signs"						X				
https://111.nhs.uk	An NHS non-emergency medical advice service						Х				
https://www.neuronati on.com/	An app with exercises to improve memory, strengthen attention, increase the speed of thought and train logical thinking. Both free and paid-for games are available.							X			
https://www.peak.net/	An app with games that test your focus, memory, problem solving, mental agility and more. Free to use but can only play once a day							X			
https://invidious.fdn.fr/ watch?v=EENsbqcbDc4	ICUSteps webinar on delirium							Х			

https://www.icudeliriu m.org/patients-and- families/cognitive- impairment	Information on cognitive impairment after ICU by ICUDelierium.org					X			
https://www.youtube.c om/watch?v=g50VsYj90 zM	YouTube video on cognitive and psychological problems after ICU admission					X			
https://constanttherapy health.com/constant- therapy/	An app with speech, language, and thinking exercises. The app will customise a programme tailored to your recovery goals. A free trial is available but payment required after					Х			
https://www.icudeliriu m.org/patients-and- families/overview	Online information about ICU and delirium					Х			
https://www.mycogniti on.com/	A brain training app to help you think faster, focus better, and improve decisionmaking and memory.					X			
https://icusteps.org/ass ets/files/information- sheets/delirium.pdf?q=f iles/booklet/delirium.pd f	ICUSteps delirium information					X			

https://www.criticalcar erecovery.com/Search.a spx?tag=114	Pain information from the critical care recovery website					X			
https://www.criticalcar erecovery.com/x11i84/	Pins and needles information from the					Х			
numbness and pins and needles.aspx	critical care recovery website								
https://painconcern.org	Online information about managing pain via					Χ			
rany.	a link to								
huss H see 20 select	painconcern.org.uk								
https://www.criticalcar	Information video on					Х			
erecovery.com/x19l212 /pacing for pain(1).asp	the technique of pacing to help manage pain								
	from the critical care								
X	recovery website								
https://www.nhsinform	information and					Χ			
.scot/illnesses-and-	guidance on chronic					^			
conditions/mental-	pain from NHS Inform								
health/mental-health-									
self-help-									
guides/chronic-pain-									
self-help-guide									
https://www.atlantiche	Information on post-					Χ			
alth.org/conditions-	intensive care syndrome								
treatments/intensive-	(PICS) and post-								
care/post-icu-care-	intensive care syndrome								
center/pic-	– family (PICS-f) from								
<u>syndrome.html</u>	Atlantic Health System								

https://www.medicalne wstoday.com/articles/p ost-intensive-care- syndrome#summary	Summary of PICS from Medical News Today					X			
https://my.clevelandclin ic.org/health/diseases/2 1161-post-intensive- care-syndrome-pics	Information on PICS and PICS-F from the Cleveland Clinic					X			
https://www.youtube.c om/watch?v=QyF8bknb Ai0	Information video describing PICS					Х			
https://www.sccm.org/ MyICUCare/THRIVE/Pos t-intensive-Care- Syndrome	Information on post intensive care syndrome from THRIVE					X			
https://icusteps.org/ass ets/files/information- sheets/nutrition-at- home.pdf	ICUSteps guide on nutrition after ICU					X			
https://icusteps.org/ass ets/files/information- sheets/tips-on-eating- problems.pdf	ICUSteps guide on eating problems after ICU					X			
https://www.bda.uk.co m/resource/nutrition- at-home-after-critical- illness.html	Online information about nutrition at home after critical illness produced by the Association of UK Dietitians					X			

https://www.ficm.ac.uk /index.php/forpatients/ further-patient- resources https://www.cc- sn.org/ files/ugd/4a06e d_90a1cb7271154131a e92a717db3613e8.pdf	Video on nutritional advice after ICU from the Faculty of Intensive Care Medicine Nutritional advice after ICU					x			
https://patient.info/me ntal-health/insomnia- poor-sleep	Online information about how to improve your sleep					X			
https://pzizz.com/	An app to help you fall asleep and stay asleep					Χ			
https://www.criticalcar erecovery.com/x14i54/s leep_disturbances.aspx	Online information about sleep disturbances and strategies to help improve these from the critical care recovery website					X			
www.criticalcarerecover y.com/x30i108/problem s_sleeping.aspx	Online information about problems sleeping from the critical care recovery website					X			

https://www.nhsinform .scot/illnesses-and- conditions/mental- health/mental-health- self-help-guides/sleep- problems-and-	Self-help information on sleeping problems from NHS Inform				X			
insomnia-self-help- guide/								
https://www.cc- sn.org/ files/ugd/4a06e d_be6b4c1d739348a2a 9dc00ee94514d2b.pdf	Self-help guide on sleep				X			
https://www.criticalcar erecovery.com/x14i53/f lashbacks.aspx	Online information about flashbacks following critical care from the critical care recovery website				Х			
https://www.ficm.ac.uk /forpatientsrecoveryaft erintensivecare/hallucin ations-following-a- critical-care-admission	Online information about hallucinations following critical care from the Faculty of Intensive Care Medicine				X			
https://www.youtube.c om/watch?v=0XCmCG6 sn3w	Video on managing flashbacks using the safe place technique				X			
https://www.criticalcar erecovery.com/x19l211 /pacing for fatigue(1).a spx	Information video on the technique of pacing for managing fatigue				Х			

	from the critical care								
	recovery website								
	recovery website								
https://www.acprc.org.	Information sheet on					Х			
uk/Data/Publication_Do	energy conservation								
wnloads/GL-	from the Association of								
03EnergyConservation(Chartered								
<u>1).pdf</u>	Physiotherapists in								
	Respiratory Care								
https://www.nhsggc.or	Guidance on energy					Х			
g.uk/media/261711/23	conservation from								
2434 2 0-energy-	Greater Glasgow and								
conservation.pdf	Clyde NHS services								
https://icusteps.org/ass	ICUSteps guide on					Х			
ets/files/information-	breathing problems								
sheets/breathing-	after ICU								
<u>problems.pdf</u>									
huss H and the	Describited by a set of the					\ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \	-		
https://www.plymouth	Breathing 'exercises ' for					Х			
hospitals.nhs.uk/downl	shortness of breath								
oad.cfm?doc=docm93jij	from the Association of								
m4n8782.pdf&ver=122	Chartered								
<u>79</u>	Physiotherapists in								
	Respiratory Care								
https://www.plymouth	Positions of ease for					X			
hospitals.nhs.uk/downl	shortness of breath								
oad.cfm?doc=docm93jij	from the Association of								
m4n8783.pdf&ver=122	Chartered								
<u>80</u>	Physiotherapists in								
	Respiratory Care								

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https://www.plymouth	The active cycle of							Χ					
hospitals.nhs.uk/downl	breathing techniques to												
oad.cfm?doc=docm93jij	aid secretion clearance												i l
m4n8784.pdf&ver=122	from the Association of												i l
<u>81</u>	Chartered												
	Physiotherapists in												i l
	Respiratory Care												
https://abscent.org/nos	Help for those with							Χ					
ewell	their sense of smell												
	affected												
https://www.fifthsense.	Help for those with							Χ					
org.uk/	their sense of smell												
	affected												
https://www.hearinglin	Information on hearing							Χ					
k.org/	loss and services												
	available												
https://www.britishvoic	British Voice Association							Χ					
eassociation.org.uk/free	website's directory of												
voice-clinics.htm	NHS voice clinics												
													
https://www.accessable	Website to search for								Χ				
.co.uk/	places which are												
	accessible for people												
	with debilitates												
https://www.gov.uk/dri	Online government								Χ				
ving-medical-conditions	information about												
	returning to driving												
	after critical illness												
https://www.euansguid	Wheelchair accessible								Χ				
e.com/	places with reviews												
https://www.cruse.org.	Website for Cruse, a									Χ			
uk/	bereavement support												
	service												
	1												

	T	 				 			 	
https://www.goodlifede	Good life, good death,						Χ			
athgrief.org.uk/content	good grief website.									
/support/	Advice for before and									
	after death and dying.									
	Targeted to a Scottish									
	audience, however, has									
	advice which is non-									
	regional									
https://www.gov.uk/be	UK government						Χ			
reavement-support-	information available on									
<u>payment</u>	financial support									
	following bereavement									
https://www.gov.uk/fu	UK government						Χ			
neral-payments	information available on									
	financial support for									
	funeral costs									
https://www.cc-	Self help guide on						Χ			
sn.org/ files/ugd/4a06e	bereavement									
d_12c08cd140b04e5c9b										
bf65f7b42a3bc9.pdf										
https://www.criticalcar	Links to family support							Χ		
erecovery.com/Search.a	from the critical care									
spx?tag=257	recovery website									
https://icusteps.org/sup	Support links via the ICU							Х		
port	Steps website							^		
	•									
https://healthunlocked.	Health unlocked - social							Χ		
<pre>com/search/posts?quer</pre>	network platform with a									
<u>y=intensive%20care&pa</u>	page dedicated to ICU									
ge=1&community=all										

	T	1	I	1	1	т г	-	Т	1	1	-			
https://icusteps.org/sup	Link to the Health											Х		
port/online-community	Unlocked social network													
	page for ICUSteps													
https://www.facebook.	Post intensive care											Χ		
com/groups/227842144	syndrome Facebook													
513131/	group													
	Facebook account for											Х		
https://www.facebook.	the Critical Care Support													
com/groups/234965208	Network													
345502														
1 11														
https://connect.mayocli	Online support group											Χ		
nic.org/group/intensive-	specific to ICU													
<u>care-icu/</u>														
https://www.exi.life/	iPrescribe app - uses												Х	
	information on the													
	user's current health													
	and prescribes a													
	graduated and													
	personalised exercise													
	programme													
https://www.criticalcar	Information video about												Х	
erecovery.com/x11l189	how to increase activity													
/how do i increase th	levels when at home													
e amount of activity i	from the critical care													
m doing.aspx	recovery website													
	,													
https://www.abs.it/ii	NUIC information as													1
https://www.nhs.uk/co	NHS information on												Χ	
nditions/nhs-fitness-	exercises, including													
studio/?tabname=aerob	beginner and higher-													
<u>ic-exercise</u>	level exercise classes													

	and programmes. Also includes a couch to 5k running programme								
https://www.nhs.uk/liv e- well/exercise/balance- exercises/	NHS balance exercises for beginners and those at an intermediate level							Х	
https://www.nhs.uk/liv e- well/exercise/strength- exercises/	NHS leg strengthening exercises for beginners and those at an intermediate level							Х	
https://www.bbc.co.uk/ programmes/p087wdd m	10 minutes exercise videos designed for older people from the BBC							Х	
https://www.csp.org.uk /public-patient/find- physiotherapist/find- physio	Chartered Society of Physiotherapy - find a physiotherapist							Х	
https://www.disabilitys nowsport.org.uk/	An organisation which supports people with disabilities enjoy snow sport							Х	
https://www.nhs.uk/liv e-well/exercise/	Exercise advice from the NHS							Х	

Tarrest III	Bltlt.t						1	.,	$\overline{}$
https://www.nhs.uk/Liv	Physical activity							Х	
<u>e-</u>	guidance for older								
well/exercise/exercise-	adults from the NHS								
guidelines/physical-									
activity-guidelines-									
older-adults/									
https://www.nhs.uk/liv	Flexibility exercises							Χ	
<u>e-</u>	from the NHS								
well/exercise/strength-									
and-flexibility-									
exercises/flexibility-									
exercises/									
https://www.nhs.uk/liv	Seated exercises from							Χ	
ewell/fitness/document	the NHS								
s/NHS sitting exercise.	the itilis								
pdf									
https://www.nhsinform	Exercises for shoulder							Χ	
								^	
.scot/illnesses-and-	problems from NHS								
conditions/muscle-	Inform Scotland								
bone-and-									
joints/exercises/exercis									
<u>es-for-shoulder-</u>									
problems#introduction									
https://yogipod.co.uk/o	Online yoga classes							Х	
nline-yoga/	, , ,								
https://www.plymouth	Chartered Society of							Х	
hospitals.nhs.uk/downl	Physiotherapy advice								
oad.cfm?doc=docm93jij	for patients discharged								
m4n8785.pdf&ver=122	from hospital on								
<u>82</u>	increasing physical								
	activity								

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https://nfsuk.org.uk/	A charity helping those										Х	
	affected by necrotising											
	fasciitis and raising											
	awareness about this											
	condition											
https://sepsistrust.org/	Homepage for the										Χ	
	Sepsis Trust –											
	promoting awareness of											
	sepsis, and providing											
	support to those											
	affected by it											
https://www.asthma.or	A charity dedicated to						Ţ				Χ	
g.uk/	improving the health											
	and well-being of											
	people in the UK whose											
	lives are affected by											
	asthma.											
https://www.bhf.org.uk	Charity providing										Χ	
L	information and											
	support on heart health											
https://www.brake.org.	A road-safety charity										Χ	
<u>uk/</u>	dedicated to stopping											
	deaths and injuries on											
	roads and caring for											
	people whose relative											
	or friend has been killed											
	or injured on the road.											
https://www.colostomy	Providing support and		<u></u>								Х	
uk.org/	information to anyone											
	who has a colostomy.											
https://www.diabetes.o	The largest charity in										Χ	
rg.uk/	the UK for the care and											
	Į.			1	<u> </u>							

	treatment of people with diabetes									
https://www.headway. org.uk/	A charity that supports people with brain injuries and the people who care for them.								X	
https://www.meningitis now.org/	Support and information on identifying and recovering from meningitis.								X	
https://www.spinal.co.u k/	A support charity for people suffering from spinal-cord injuries.								Х	
https://www.stroke.org .uk/	An organisation that provides support and information on strokes and guidance on coping								X	
https://static1.squaresp ace.com/static/5ba4be3 8a56827832703eb7a/t/ 5e751e6a6c6c78290a14 e41a/1584733884059/L ife+After+Sepsis+Guide +- +Brochure+by+the+Eur opean+Sepsis+Alliance. pdf	Life After Sepsis information booklet from the European Sepsis Alliance								X	

https://www.asthma.or g.uk/advice/nhs- care/emergency-	ICU and recovery information specific to individuals with asthma							X	
asthma-care/intensive- care/									
https://www.headway. org.uk/media/8821/cop ing-with-memory- problems-practical- strategies-factsheet.pdf	Information leaflet on coping with memory problems following a brain injury							X	
https://meassociation.o rg.uk/	Fatigue and long covid help from the ME Association							X	
https://sepsistrust.org/ about/about- sepsis/patient-stories/	Patient experiences of sepsis from the Sepsis Trust							X	
https://sepsistrust.org/ wp- content/uploads/2020/ 06/Critical-Care- Booklet-220420.pdf	Sepsis Trust recovery guide for after ICU							Х	
https://www.alcoholics- anonymous.org.uk/	Alcoholics Anonymous information – a number of ICU admissions are alcohol related. Support and advice if you think you or someone you know is drinking too much alcohol							X	

https://www.bhf.org.uk /informationsupport/he art-matters- magazine/news/corona virus-and-your- health/long-covid	British Heart Foundation website on long COVID								X	
https://www.blf.org.uk/	British Lung Foundation information on managing breathlessness, breathing exercises, staying active								Х	
https://www.blf.org.uk/ support-for-you/keep- active/pulmonary- rehabilitation	British Lung Foundation advice on pulmonary rehabilitation services								Х	
https://www.blf.org.uk/ support-in-your-area	Finding local support via the British Lung Foundation - breathe easy, pulmonary fibrosis and singing groups								Х	
https://sepsistrust.org/ wp- content/uploads/2020/ 06/Recovery-After- Critical-Illness-Checklist- V2.pdf	Checklist for post-ICU recovery from the Sepsis Trust								Х	

https://sepsistrust.org/ wp- content/uploads/2021/ 05/Recovery-Wellbeing- Diary.pdf	ICU recovery diary from the Sepsis Trust								X
https://icusteps.org/ass ets/files/information- sheets/brain-injury.pdf?	Information sheet from ICUSteps on acquired brain injury								Х
https://www.macmillan .org.uk/	Cancer-related information								Х
https://www.selfhelp.or g.uk/COVID- 19 Survivors Group U K	Self-help UK COVID-19 survivors group								Х
https://edition.cnn.com /2022/04/25/health/pts d-covid-icu-families- wellness/index.html	Article from CNN about PTSD in families of COVID ICU patients								Х
https://www.healthline.com/health-news/ptsd-common-among-family-members-of-people-in-icu-with-covid-19	Article about COVID-19 and PTSD								Х

https://www.hopkinsm edicine.org/health/cond itions-and- diseases/coronavirus/co ronavirus-recovery- breathing-exercises	Tailored towards COVID patients - breathing advice and exercises								Х	
https://www.plymouth hospitals.nhs.uk/downl oad.cfm?doc=docm93jij m4n8916.pdf&ver=124 89	Rehabilitation booklet from the University Hospitals Plymouth NHS Trust								Х	
https://covid19.criticalc arerecovery.com/	Information on a range of topics related to ICU recovery following COVID-19								X	
https://covidpatientsup port.lthtr.nhs.uk/#/less ons/7iKjxFnj8B8T44HpK hLsfkIPXxpTtxww	Information about swallowing difficulties after COVID-19								Х	
https://www.rcot.co.uk /file/6694/download?to ken=sbwRd3Y0	Information leaflet on how to conserve your energy after critical illness produced by the Royal College of Occupational Therapists and the Intensive Care Society								Х	

https://www.rcot.co.uk	Information leaflet on	l I	1	1	l	1	1 1	j	I	I I		х	ı
												^	
/recovering-covid-19-	how to manage fatigue after COVID-19												
post-viral-fatigue-and-													
<u>conserving-energy</u>	produced by the Royal												
	College of Occupational												
	Therapists and the												
	Intensive Care Society												
https://www.yourcovidr	Information about											Х	
ecovery.nhs.uk/your-	family/carer well-being												
wellbeing/family-	after a relative has been												
friends-and-carers/	diagnosed with COVID-												
	19												
https://www.youtube.c	An online video about											Х	
om/watch?app=desktop	voice problems after												
&v=Y9QqYuHhSkI&feat	COVID-19 produced by												
<u>ure=youtu.be</u>	the Royal College of												
	Speech and Language												
	Therapists												
https://clearyourhead.s	Mental health advice											Х	
cot/	from the Scottish												
	government. Targeted												
	towards our time spent												
	in the pandemic,												
	however, there is also a												
	lot of general mental												
	health advice												
https://covidpatientsup	Online information											Х	
port.lthtr.nhs.uk/#/	about recovery after												
	COVID though full of												
	information which is												
	generally applicable												
	after ICU or illness												
	arter led of filliess				l				l				

https://sbuhb.nhs.wales /recovery- wellbeing/about- recovery- wellbeing/covid-and- long-covid-recovery- therapy-information- pack/	Information about recovery after COVID-19 or illness/hospital stay in general, from the Swansea Bay University Health Board								X	
https://selondonccg.nhs .uk/wp- content/uploads/2021/ 02/2601-Caring-for- yourself-after- coronavirus.pdf	Advice for recovery after COVID however much of the information could be applied to recovery after any illness.								Х	
https://www.blf.org.uk/ support-for-you/long- covid/managing-a- cough	British Lung Foundation information on managing a cough								X	
https://www.cruse.org. uk/understanding- grief/grief- experiences/traumatic- loss/coronavirus- bereavement-and-grief/	Cruse bereavement support - COVID specific								Х	
https://www.facebook. com/groups/longcovid/	Facebook long COVID support group								Х	
https://www.longcovid. org/	Long COVID support website homepage								Х	

https://www.som.org.u k/COVID- 19 return to work gui de for recovering wor kers.pdf	Advice on returning to work after COVID and with long COVID							Х	
https://www.youtube.c om/watch?v=8 AKe07J 7tE	Video on experiences of ICU during the COVID pandemic							X	
https://www.csp.org.uk /frontline/article/we- answer-your-questions	Information on post- viral fatigue from the Chartered Society of Physiotherapy							Х	
https://www.plymouth hospitals.nhs.uk/downl oad.cfm?doc=docm93jij m4n8915.pdf&ver=124 88 https://www.youtube.c	Link to COVID-19 Rehabilitation Handbook from University Hospitals Plymouth NHS Trust Video of carer speaking							Х	X
om/watch?v=9qDIOu7s	of her experiences								^
https://www.youtube.c om/watch?v=Ea1zQbDE lyo	Experiences of flashbacks								X
https://www.youtube.c om/watch?v=KLiGC9W wAfo&t=155s	Video of patient and family caregiver's experience of going home								Х
https://www.washingto npost.com/health/2021 /11/12/covid-icu- intensive-care- syndrome/	Patient accounts of ICU								X

https://www.thoracic.o	Dationt ovneriences	 	1	1	ĺ			I	1	1 1		l I	νI
	Patient experiences -												Х
rg/patients/par/par-	various, including												
publications/index.php	subjects such as ICU												
	delirium												
https://www.plymouth	Patient's stories												Х
hospitals.nhs.uk/rehab-													
stories													
https://www.theatlantic	Personal experiences of												Х
.com/science/archive/2	ICU and a little on												
020/04/life-after-the-	recovery												
icu/610384/	100000.												
104/010301/													
https://healthtalk.org/	A website covering a												Χ
	wide variety of personal												
	experiences of health												
	and illness. It includes												
	video interviews of												
	people who have been												
	through different												
	illnesses and includes												
	sections for intensive												
	care patients and their												
	relatives.												
https://healthtalk.org/i	Health Talk webpage on												Х
ntensive-care-	the emotional impact of												
experiences-family-	ICU on friends and												
friends/emotional-	family												
impact-on-family-and-	,												
friends													
11101100													

https://healthtalk.org/intensive-care-experiences-family-friends/supporting-and-caring-for-the-ill-person-at-home	Health Talk webpage on supporting and caring for someone when they come home								X
https://www.ficm.ac.uk /forpatientsrecoveryaft erintensivecare/going- home-following-a- critical-care-admission	The Faculty of Intensive Care Medicine webpage on going home after a critical care admission, including people's personal experiences								X
https://www.icudeliriu m.org/patients-and- families/patient- testimonials	Patient experiences of ICU and delirium								Х
https://healthtalk.org/intensive-care-patients-experiences/discharge-and-moving-on	Patients' experiences of moving on after ICU from Health Talk								Х
https://healthtalk.org/intensive-care-patients-experiences/icu-follow-up-care	Patients" experiences of ICU follow-up care from Health Talk								Х
https://healthtalk.org/intensive-care-patients-experiences/physical-recovery	Patient experiences of Physical recovery following critical illness from Health Talk								X

	1	 1	1						
https://www.youtube.c	Video of patient								Χ
om/watch?v=I6FlpZGbf	experience of ICU, from								
HA&t=988s	the Intensive Care								
	Network. The presenter								
	also speaks about the								
	benefits of drawing and								
	music to help with PICs								
https://healthtalk.org/i	Online videos of								Х
ntensive-care-	family/friends talking								
experiences-family-	about their experiences								
friends/overview	of having a loved one in								
	critical care from Health								
	Talk								
https://www.criticalcar	Online information from								Χ
erecovery.com/x27/oth	people who have been								
er peoples stories/	critically ill and their								
	experiences of returning								
	home after being in								
	hospital. From the								
	critical care recovery								
	website								
https://fromdeliriumtor	Blog of ICU experience								Х
eality.com/	particularly delirium								
	· ·								Х
https://podcasts.google	Podcast by Mark								^
.com/feed/aHR0cHM6L	Hudson, a former ICU								
y9hbmNob3IuZm0vcy9j	patient. In it he speaks								
MTU5N2M0L3BvZGNhc	with Kate Tantam; an								
3QvcnNz	ICU Sister in Plymouth,								
	about the ways staff are								
	working towards								
	improving patients'								
	experiences in ICU.								

https://www.itv.com/n	Patient experience of								Χ
ews/granada/2020-05-	ICU. Interview on ITV								
21/help-for-virus-	news								
patients-who-ve-been-									
<u>in-critical-care</u>									
https://healthtalk.org/i	Health Talk website -								Х
ntensive-care-patients-	patient experiences and								
experiences/overview	information based on								
	ICU and recovery								
https://healthtalk.org/i	Personal accounts of								Χ
ntensive-care-	the experiences of								
experiences-family-	family and friends of								
friends/emotional-	ICU patients from								
impact-on-relatives-	Health Talk								
friends-in-icu									

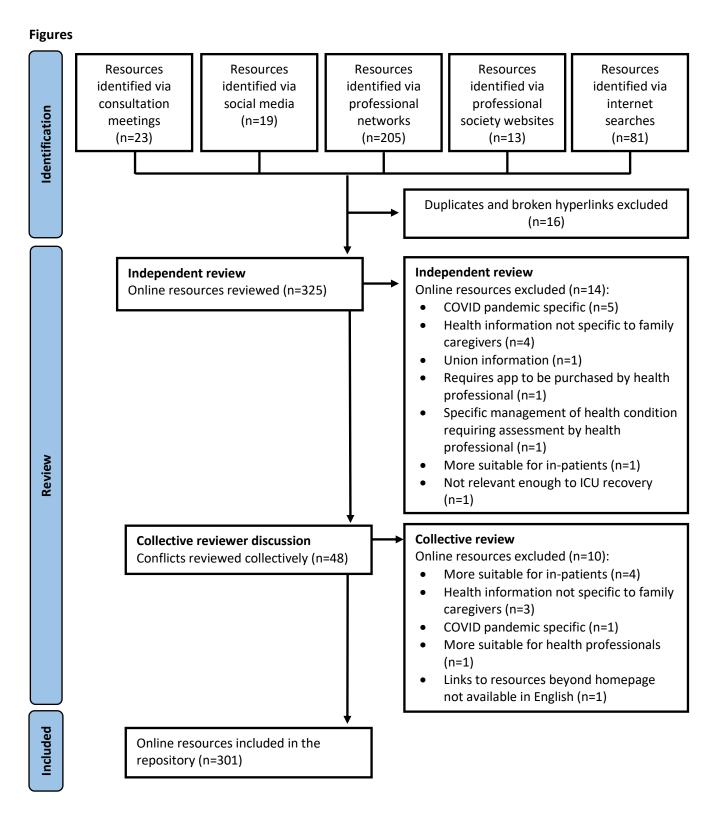


Figure 1 Flow diagram of the review process. This flow diagram demonstrates the number of online resources identified by each search method, the number excluded at each stage of the review, and the reasons for exclusion.