MAP: Pavillon V2 Map description SCOPE SUMMARY Journey map with focus on service blueprint from the perspective of healthcare professionals Key phases Deaths Diagnosis and active treatment of the disease Referral to a mobile palliative care team (EMSP) Initial Consultation Visit Follow-up actions (including critical events) Hospitalization Terminal phase Illustration nent follow-up much appreciated

HENKO NET

Moving to EHPAD

thoughts and

feelings of the

Actions of the

healthcare

professional

Experience

Pain Points of

Pain points of

Pain points of

the healthcare

professional

Ideas and

(patient)

Ideas and

(relative)

Ideas and

Opportunities

(healthcare

professional)

Opportunities

Opportunities

Communication by e-mail, telephone

But I couldn't have done it on my own (...)".

comfort and support at an earlier stage.

recovery. It's normal!"

circuits that serve no purpose in the end."

he's at ease with the written word. Yes, much softer (...) "

"It's mainly that you see with my oncologist, who's quite young, he's very internet-

minded and so we found a way. So, I don't know, was he uncomfortable with the

contact? I don't know. I don't know, maybe. In any case, it came gradually with him. I

sent him e-mails (...) That made it easier for us to get in touch. And now you can see,

"Helping people with administrative formalities, that would be good, I think (...) you

could relieve the misery of poor people who are sick, who suffer (...) I wouldn't have

had my daughter (...) I'd be dead. Because I would have sent everything to the plot.

And then Castorama wasn't far, you buy 3 meters of rope, it's good. It's a done deal.

Earlier palliative care, to avoid repeated hospitalizations, to provide

Palliative care could be initiated earlier, if the situation

"In my husband's case, I'm convinced that he could have been offered palliative care

earlier (...) And then I understood afterwards (...) if they weren't keen to hospitalize

him, it's because they knew it was hopeless. They weren't "interested" in it, to put it

mildly (...) But why wasn't I referred to palliative care earlier? Because I would have

understood (...) You have to give a chance, the beds, to those who have a chance of

It's best to help them deal with the situation as soon as possible.

"There's no point in delaying. On the other hand, the fastest, most advanced care possible, both for the families and for the patients, is pointless with these hospital

were clearly explained to patients and their families.

Early support with administrative procedures, treatment, etc.

the relative

the patient

relative

longer possible to stay at home".

Dissatisfaction with follow-up

was worse

another layer."

Palliative care proposal

"I couldn't move around anymore, I was so limited in my movements that it was no

"Let's just say that it's really been the last 2 years where it's been very complicated,

where actually, well, we'd have a lot to say... Because we've been to a lot of hospitals.

We've seen a lot of doctors, but then, disappointments, hello, thank you, goodbye!"

"The hospital, well every time he went, it seemed like every time he came back it

I don't get it," he says, "the guy's already taken a beating and now we're adding

"So my oncologist asked me if I wanted to be accompanied by a palliative care

team. He made it clear that it wasn't because I was on the verge of death, but that it

was if I needed help, if something happened (...) I think that if he had just told me

Technology takes up too much space during consultations VS not

He says, "Who are you, sir? He hadn't seen me. He hadn't seen me. So yes, the

clinical aspect of the relationship, in general, I'm very satisfied with anything

ask you who you are, it raises questions, I won't go any further, but it raises

The patient can't manage everything (appointments, treatments,

administrative procedures), and needs to delegate (you have to be

"I'm honest with my family, I gave up. I just couldn't take it anymore. The less I do

with computers, the better I feel. It's not my generation at all (...) I've passed the

"I'm forced at times, but with the mutual insurance company, for example, to communicate with mutual insurance companies, I swear it's almost a feat with the

"It was no longer tolerable. It wasn't viable for my son, it wasn't viable for my

"So she had the damn stroke. That knocked me on the head, of course. Because she

took care of everything, the house, the food, everything. I wasn't used to that!

"I was having tests done, we could see that it was dropping (...) I was starting to

have little haemorrhages on the left and right (...) And in 2023, I made the decision, after consultation with the children, to move closer to my daughter (...) So it wasn't

"You uproot an oak tree that's 30 metres high, replant it and it has no chance of growing back. I'm an uprooted oak. Even with all my efforts, it's complicated. I'd

"It's very discouraging for the caregiver, because you have to be everywhere. Well, I

wanted to manage everything at the same time. But it's true that, yeah, I really got

Improving the announcement of the deterioration of the disease with

"At the time of palliative care, when palliative care is announced, me, when it was

announced to me, it was because I asked the doctor to tell me what it was."

orientation of the project towards palliative care

wanted to keep working, because if I didn't, I'd probably lose my head too, so I

able to vs. you have to prevent caregiver exhaustion).

baton (...) they take care of all the administrative stuff".

Internet (...) Fortunately I have my son and my neighbor..."

"I go out, having forgotten my umbrella. I come back a minute later. I open the door.

medical. Still... I would condemn the place occupied by technology in consultations

(...) when all the same, when everyone is there, welcoming you, you come back, they

enough human and social contact with the patient

questions!"

neighbor."

an easy decision to make (...)"

Exhaustion, loneliness

into it with the GP.

rather have died at home over there.

palliative care, I would have said to myself once again, this is it, it's over."

Illustration					HOSPITAL		
Actions du patient	 Medical appointments Heavy treatments Medical examinations Regular hospitalizations "I refused treatment for at least a year or two () I pulled too hard on the rope. But I didn't want to give up. We don't go backwards in parachutists. You move forward or you stay put. So, I said, you've got to be abit more serious. So [the Doctor] told me, we've going to attack () psychologically I felt diminished, physically () I found it hard to cope () It worked on me enormously () I stopped lpainting classes. I stopped working completely. I couldn't do it any more () because my morale was gone. I knew I had a bloody diseases." "Medication is like everything else. There's good and there's bad. But right now, there's more bad than good () For me, it's getting tiresome. Too many side effects itching, loss of sight () I said to the Doctor] but how is this going to end, the retina is being eaten away, she told me it's not serious, it's mortal, it's the chema. Is it? How will it end? Ah well, you'll end up blind. They tell you that at 10 in the morning, you're in good spirits for the day!" Suicide attempt and/or request for euthanasia and/or request for PC after diagnosis of incurability "It's been a while since I asked my daughter to take me to Spain or Creece. And she told me, I'll do all the paperwork, but I'm not the one to go with you. So but then she said to me, you know Mom, you'll only do the paperwork when you really can't, when you can't live anymore, you'll have nothing." "When someone commits suicide, all the people around them, the caregivers, the family and so on, say to themselves, What didn't we do to make him do that? So that's why I've rationally eliminated, let's say, this solution." Announcement shock "So I grabbed my radio, got back in my car and in the parking lot, what did I do? I read the conclusion. I couldn't understand it, of course. I looked on the Internet. And what came up?	Denial, anxiety, fear I'm going to die I don't want to die So the palliative, right away, we think the worst. Honestly, We think the worst, but in fact, no. We're not necessarily at the end of the tunnel (_), We're not necessarily at the end of the tunnel (_). It's also important because people immediately imagine palliative care and death. It's an apprehension, no doubt about it. It's an apprehension. I've never hidden that from you* The situation is more or less well understood depending on the case "What happens the day it gets worse, how do we switch to palliative care?" Lack of anticipation in setting up support (all players in the ecosystem are impacted) "The doctor] didn't want to hear about it (_) It's too early! So I told him I'd always rather be 10 minutes early than 5 minutes late." "Palliative care] It's comforting You can see that you're supported (_) I had very poor care before (_) Imy CP used to tell me I was here for life (_)! "I lived in a small village (_) It's not a medical desert Because there were three doctors in the practice But, well, they're overworked maybe they're not really competent in this [palliative care]. "[Earlier initiation of palliative care] It's true that it would certainly have reassured me (_) It supports me morally." Palliative care at home VS hospital "Ah yes, because the hospital, even if they are very nice (_) the food! I lost 3 kilos in hospital. I gained them back at home. It's so bad that even if you're hungry, it spoils your appetite. It's scandalous. These are people who are sick, who often aren't very hungry to begin with. And what triggers the appetite? Smells and sights. What they bring doesn't have a smell, and the sight alone takes away your appetite. It's frightening, it's a trick, it's outrageous." "In the hospital, if you suddenly want something, it's a trick, it's outrageous." "In the hospital, if you suddenly want something, it's a trick, it's outrageous."	Face-to-face discussion with a palliative care team + GP + relatives at home Patients and families would like more information on the various stages of the palliative care "calendar". "starting point of the last stage" "an essential visit" "get to know the people we deal with physically; and gain an understanding of the possible future course". "The question thad asked the Doctor is to the extent that it's getting worse, do you go all the way through the circuit or not?" "The time to wipe my ass I want to get it over with". "accompanying death without suffering "I don't want to last at all costs". Relief (I'm taken care of, I'm not alone) "We're here for support. They're here to explain things to us. That's the first report we had, and you explained all that to me." Patients want to be listened to, to be heard, not to be bullied, but they don't want to be spared either.	Breaking out of isolation and loneliness "L.) the heart of the association was to help people in the Médoc suffering from cancer to get out of their isolation (_) once a month, I go there, have a chat, drink a coffee and eat a little cake. And I find it interesting because the atmosphere is not. Levey, So that's that. I'm not the poor me, I've got cancer, gnagnagna type (_)! Figure if my days are numbered, they might as well be good ones. As happy as possible and as well as possible: "Unfortunately, I don't do anything except when my eldest son comes to pick me up, so sometimes he comes to pick me up to go and eat at his place, to go out a bit. My girlifriends came to pick me up a fortright ago, we went to the ocean, and it did me a world of good, and a lot of laughter (_) I'm there now." Thave at least one visit every week." "Dean-Luc] comes at least once a week, if not twice." Palliative care is a real added value "ves (PC is a real plus) because at the very beginning, there was the operation, there was the radiotherapy, I went home. Basta. I was all alone in the world. So what do you do? Well, the physiotherapist, yes, because the doctor could give me the prescription. But after that, I was all alone in the world. The same goes for administrative support, whether it's assistance, the CAF, the thing, the thing, the MDPH, all that: "Having regular contact with different professionals also helps (_) For me, it's been It's good. Because all of a sudden. I was able to compare being alone in the world and being accompanied, it's night and day, it's like night and day, especially when you're an anxious person (_)" "I think it's important for patients. Especially since I don't have an easy situation with my family either. So It's all very important. It's little things that people might find anecdatal but it's very important." "Coday, yes, It suits me. The sits me. There's always someone listening. That's already very important. What I really like is the fact that someone can be at home quickly" "I	"Well then, maybe I'll give you some competition. It's possible that I'm going to Bordeaux for a week for palliative care. I can't remember what it's called. Just for the bathtub. When I saw the bathtub () To decompress, to get out of the cycle () I'll try to plan it when my son is in boarding school () to recharge my batteries a little () What's heavy in everyday life is the family context". Hospitalization associated with incarceration, the patient hears the teams' conversations, care is rapid Then I was incarcerated in the ward downstairs So I don't sleep much, if you like and first of all, there are only two people in each room, so when you have people undergoing chemotherapy who need to use the tollet, I can't tell you what the problem is, it's horrible and I don't sleep much, and at night I could hear certain teams talking in the corridors, I swear it doesn't cheer you up () And then the care we give you lasts five minutes during the day, it's purely commercial." HAD - hospitalization at home / escape from hospital "For me, it's much more practical, and I'm a bit fed up with hospitals, as they say. And the less I see of them, the better I feel." HAD - hospitalization at home / dying at home surrounded by loved ones "I don't want to die in an anonymous room. I don't want to die in an anonymous room, I want my children around me if possible, I don't want to spend my last days in an institution" HAD - hospitalization at home / team responsiveness "So it's true that it's also very good because it's very reassuring () they're night and day, 24 hours a day, there's the slightest problem () there's someone () they react very, very quickly." "As the treatment progressed quickly, the anxiety disappeared just as quickly.	"Me, the doctor knows my philosophical finality () the day things start to go wrong, the day I miss a step, and I start to lose all my faculties and to be, I'd say, a wreck, that I can apply for a position as a plankton in an EHPAD, life is no longer worth living. Because its only purpose is to piss off my loved ones. Well, and to suffer, insofar as despite all the painkillers you take, there comes a time when there's not much you can do about it." Don't be a burden on loved ones for too long "It's important to me and it's especially important to others. You know, it's not viable for others. They've been waiting a year for me to die."	
	"I must say I was in for a shock because I was told I was going to die in the weeks that followed."			"I can't go anywhere. I have my hairdresser come to my home. I can't cut my right toenails anymore. So a pedicurist came. I'd have to go to the eye doctor. I'd have to go to the dentist. Every time, I need an ambulance, traveling lying down, that's my problem."			

Normal life, except for pain

especially at night."

Waiting, long time

Treatment anxiety

Other occupation

Palliative care, caregiver support

Avoid overburdening caregivers

house. I've decided to stop driving myself."

grief, but I wanted to know things anyway...".

Competent service provider, caregiver for caregiver

The importance of the Internet in helping caregivers

was a site where we could find information, that would be interesting."

was able to open the good bottles for him to taste before he left" Mrs. 4.

knew where they were, and helped me enormously."

Caregiver happy to support patient at home

on follow-up actions to be implemented

with patients' doctors, even if it's not secure.

Application or revision of the personalized care plan

Coordination of healthcare professionals and teams

Social and psychological support for relatives and/or patients

Advice and proposals for therapeutic and/or non-therapeutic adaptations

"As far as they're concerned, everything's fine. And at times, it's borderline, he tells me I'm being picky

Expectation of personalized care, with homecare providers who are better qualified,

better trained, more available, more responsive, less staff turnover, fewer restrictive

"You see, I have compression stockings. Theoretically, it's the orderlies who can put them on (...) I lack

oxygen. My skin feels like cigarette paper (...) And so, I refused to let the orderlies... I told some orderlies who have false nails and very long... Well, first of all, I can't understand that care assistants have very

long false nails, but then to put on stockings, I refuse (...) And so they took it very badly (...) But I can't

"It's getting hard to eat on my own (...) And the doctor says, I've got a solution for you (...) And then she

tells me... Gastrostomy (...). A gastrostomy (...) It made me jump (...) But I said, are you kidding me? I told

"You have access to the results, but afterwards, it's always the same - there's no one to explain it to you

"I don't think we get enough help with anticipation, if we don't ask questions. But we don't know what we're entitled to (...) well, we manage a bit, because we realize that at some point there's a given problem (...) it's someone completely outside (...) who's told us, but you could do that. But in fact, I don't

"The loneliness, that's what was so heavy. Because when you're sick, you're still cutting. There's family.

"They don't understand, that people like me, who are dependent on an ambulance, there are times

"I was supposed to see the doctor, but it turned into a phone call, and I think it's still a bit average", "it's

Estey's secondary role in the urban environment (no prescribing power) can create

"When the Estey team came, it's true that it's good, we had meetings, but then nothing. Exactly, you

said we needed a connection (...) even if we'd only had a connection by phone, computer or whatever,

that would have been fine. But there was no connection. I even had to call the doctor myself, the 15, to

"And we're in the city (...) so I can't imagine the same situation in the middle of Auvergne (...) I can't

"It's true that I've always been a bit of a fireman, in fact, calling the other firemen! And that, I think,

may also come from the GP. It comes from... the teams. Well, the doctor asked that the notebook be

"I came out of that experience in tatters, that's for sure, but I wondered how people who didn't have

someone to look after them full-time managed! Because that's all I did for a year. For the last 3

"It was too fast and the hours were imposed (...) I didn't have a second to ask them a question".

"The teams (...) it's true that there's remarkable follow-up, but there's no humanized follow-up, it's not

"On the rare occasions when I've had to call on a social worker, I've asked her a question. Well, I'll have

"It takes a year to get a badge [parking for disabled people], and he was already dead when I got it (...)

Homecare nurses: "It's clear that they're not prepared for this kind of work, so they do what they can

Caregivers who have to make up for the lack of time and/or knowledge of homecare

"Sometimes the nurses, I'd say, almost had to substitute themselves completely in the acts and all

"It was huge to be able to talk to someone on the phone because I spent a long time, but infinite time on the phone, trying to reach the hospital doctor, trying to reach a nurse, trying to reach the attending

"And that, I think, could have been explained to me. Because, afterwards, I became an oxygen pro, yes, but I learned on the job. But people panic! (...) I was told not to go below 90 but, you see, afterwards I came to understand that it could go down to 85 without dying, you don't die immediately, so all this is information that should have been given to me. They should have given me a little information on how

CAPalliatif: There is a generational divide in the use of digital tools, which further

EMSP does not always know who to contact when several partners are involved,

EMSP Estey: During a critical event, when there are several partners, there is often

uncertainty about who to contact. Information circulates by word of mouth, which

HAD Bagatelle: When we intervene, we do our best to centralize all information. This

enables us to dispatch it efficiently to where it's needed. However, it's not always easy.

referrals. What's more, some calls don't go through our structure or yours (EMSP), but

rather through the 15, even though this was not the planned route. These situations

CAPalliatif: Data transmission is all the more complex in Bordeaux Métropole, as it is

HAD Bagatelle: The role of Hospitalisation à Domicile (HAD) in anticipating patients'

needs is an area for improvement. It is essential to avoid emergency treatment, often at the last minute. HAD can play a preventive role, offering follow-up care before

Anticipate the next steps, future needs, and the steps to be taken with volunteers,

"For advice (...) Precisely, when I have attacks of dyspnea, to be able to contact, for example, a room to

reassure me (...) with regard to these episodes which are very, very distressing and which are always

difficult to live with (...) Calls in case of emergency... Perhaps encouragement [for physiotherapy

exercises], motivation (...) or perhaps meditation exercises or that sort of thing (...) or sophrology (...) it's

"At the moment, I feel I don't find the need to see or talk to the psychologist. I don't call her. But when

the day comes, she'll be there. So I know that perfectly well. As I said earlier, you have to evacuate.

"No, technology is good for everything to do with better care, like finding that [PCA]. It's pretty great.

Anticipate the next steps, the needs to come, the steps to take with volunteers,

Alleviate isolation and loneliness, loss of autonomy, pain management... => a pool of professionals and structures for palliative care; practical information sheets, exchange

"If palliative care could provide a pool of nurses, orderlies, etc. who are connected to palliative care and

who could be called upon to intervene at home in the context of palliative care, that would be great.

Starting in December, I called in 2 nurses, one who came in the morning, one who came in the

"When you go to them, you don't fall on the moon, they know what it is, it saves time (...) You have to put everything on this, ambulances, nurses and all that. Create a network of people who... who we train

"I'd get up every hour to check that he hadn't lost his oxygen. It was unbearable. I was exhausted. So I ended up putting a baby camera over the bed, so I'd wake up every hour, but I'd look, I'd see the tubes

"I had bought a sort of articulated arm that held the phone for him and he would put on his music

"I'm all for new technologies. First of all, it's true that it brings speed to the transmission of information (...) but we mustn't forget that the patient is a human being, the caregivers are human beings, and we

CAPalliatif: Even as a patient, I'm not familiar with all the features of Mon Espace

Santé. Communication campaigns would be needed to promote the use of this

EMSP Estey: It would be useful to show which teams are active in care management

ESEA: Indeed, on MES, it would be preferable to include the professionals who follow

me a little text message. I've gone a bit fast, but this afternoon I've got more time."

associations, homecare workers, before returning home;

from time to time, to whom we give a minimum of information."

[sounds of waterfalls or thunderstorms that lasted 10 hours]."

mustn't lose sight of that notion, that's what I think is important."

ESEA: There's a secure messaging system in Mon Espace Santé.

of tips (more resources to help and support their sick loved ones)

evening (...) They helped me... I'm not going to be... But it was just 2 minutes 35."

Active, early psychological support for family members and caregivers

"If it was a robot that was a nurse, it wouldn't have the same effect on me at all", "Sometimes they send

Relieving isolation and loneliness, loss of autonomy, pain management...

Advice, suggested exercises, remote monitoring for reassurance

Knowing you can contact the psychologist at any time

true that I really appreciated [sophrology]".

There's too much, there's too much sometimes."

Technology cannot replace relationships

But it can't replace the human."

"information sheets"

and I could go back to sleep".

Technology cannot replace people

Use of secure health messaging

space, beyond email activation.

Enable rapid identification of resources

the patient, rather than simply mentioning "teams".

In case of critical events:

on my health space (MES).

"an oxygen card"

Follow-up:

associations and homecare workers before returning home.

more compartmentalized, with more separate intervention teams. L'Estey works

We find that some patients contact directly the mobile team doctor they have met

before, with whom they have established a relationship of trust. This dynamic of

collaboration and mutual acquaintance is essential to facilitate exchanges and

can jeopardize all the work we've already put in place.

coordination work may be compromised if the wrong person is contacted.

"It would help families, I think, to have access to a pool of nurses trained in palliative care.

possible, because it's not the same people from one day to the next, it's never the same people".

Mental workload associated with managing treatments, medical appointments,

Complicated treatment side effects and time-consuming adjustments.

Proposed follow-up visit

In case of critical events:

Not helping relatives

protocols...

Yeah, I wish we could switch places!"

take the risk because if she hurts me afterwards...".

Proposal runs counter to advance directives

you I didn't want any of that."

Technology with communication

Don't substitute technology for people

or to accompany you in discovering the result."

know what exists. I feel a bit like I'm fishing for information."

"Some patients don't want to travel to Bordeaux just for a consultation".

"Travel in fact, to go to the oncologist, to the doctor, it can be complicated."

"I don't want to know anything anymore (...) I don't even want to know".

confusion (feeling that the team is not sufficiently involved after VCI).

"No but I mean sometimes... even... it didn't occur to the nurse to call the Estey doctor!"

say, well, my husband really isn't well, we'll have to send for someone".

Caregiver who feels she has to manage everything, exhaustion

even imagine (...) the difficulty must be even greater"

well done. Well, they wrote whatever they wanted!

Liberals are too quick to intervene at home

Home follow-up not human enough

months, it was the neighbors who did my shopping for me."

to find out (laughs). And you wait. And nobody ever calls you back.

even though it was the Piñada social worker who drew up the file (...)".

"One of them called me the head nurse, so I was fine with it!"

doctor who have crazy, crazy, crazy schedules, and you can't get through..."

Homecare professionals insufficiently trained in palliative care

"I was running around too much.

"Ah yes, it was top chrono!"

Lack of responsiveness

(...) well, it's very discouraging"

Having to learn on the job

No mastery of digital tools

complicates access to care.

In case of critical events:

can lead to information being lost.

mainly in the home.

critical care is reached.

to manage oxygen."

Follow-up:

workers, exhaustion

administrative paperwork, etc.

Lack of anticipation

Difficulty getting around

Results anxiety

Rural environment?

Lack of clarity at the outset can have an impact on the first meeting with

"Do you remember when you first came? It was very hard for me (...) when you came, it

wasn't yet clear in my head, so when (...) you started asking questions, how do you want

the end to go? Do you want to keep him alive until the end? Do you want us not to go

on? It was very violent (...) That's why I said to myself, maybe we need to find a way (...) to

The words used, and how they are understood by the patient and those

"When you've got your head in the game, as a caregiver as I have been for over 10 years, you perhaps lose the meaning of words a little. Maybe, as cruel as they may be, add the

terms 'end of life', 'end-of-life assistance' or things like that... Because after a while,

palliative care becomes blurred, it loses its meaning for me... I just didn't know where I

"When care begins in palliative care, we need to find a way of ensuring, even if it means

a shrink interviewing the patient or caregivers, that psychologically, even if there is

EMSP Estey: One point of concern is the use of the "urgence palliative"

form, which is no longer really used with the evolution of emergency

software. What's more, with the DMP (Dossier Médical Partagé - shared

medical record), it's difficult to highlight the report, which can get lost

CAPalliatif: Social and medico-social establishments have their own

for homecare, but the transmission of information with these other

Ensure that the situation and the palliative care pathway are well

understood and demystify the terms palliative care to limit anxiety and/or

misunderstandings (the patient pathway as a tool; psychological support

as support; more communication and information campaigns for the

general public) => share the "calendar" (the patient pathway and the

Early identification of the resources available to the patient's family and

Early anticipation of patient and/or caregiver loneliness and isolation

and/or caregiver burnout, with earlier psychological care for patients

Giving caregivers the means to support their patients and prevent burnout (sharing information and best practices, fact sheets, reservoirs of

Saying things: "What's important is to **understand where we're going**! And what's

important is that we're not alone (...) we're not children, I mean, death is part of life too,

so we have to face it one way or another (...) we're helped more by talking to us (...) it also

gives us the opportunity to make arrangements a little more in advance...". Mrs 4

friends (to quickly compensate for complex family situations / exhausted,

stages) and check that it is understood.

toxic, absent caregiver / patient caregiver)

and/or caregivers.

professionals, structures, etc.).

communication and transmission software. PAACO is being developed

among the other reports. We're still thinking about it.

establishments is also complex and can pose problems.

denial, even if we refuse by all means to face reality, that at least the terms are

close to them, are very important aspects of care for caregivers.

"That's it, there has to be an announcement, I think it's very important."

understood, that the situation is understood."

the palliative care team (VCI).

make sure that everyone understands."

stood anymore."

when vou can't find an ambulance."

true that the difficulty lies in the distance".

Loneliness

"It's not less technology. It's just as much communication, if not more."

Remote contact

Follow-up:

either".

Denial, inability to control

"There's a kind of denial on our part, we don't want to accept it, and then maybe there's

a lack of, well, I don't know if it's a lack of training for the people involved, whoever they

may be, to perhaps put on... I know it's perhaps difficult... but to explain better (...) even

we don't know, that we're putting things in place that we don't control, is disturbing."

Comprehensive assessment of patient needs and definition of a

personalized care plan

Assessment of inclusion, complexity and urgency criteria

Organization of a home visit with healthcare professionals

The patient must accept the situation and the associated follow-

Care is not sufficiently personalized. Homecare

workers do not have enough time to devote to

"What there is is that there is a general protocol for all patients at the end of

Difficulties in obtaining patient consent and/or GP validation to

Coordination work is complicated in urban areas because of the

many different teams involved VS too much tinkering in rural

areas because of a lack of resources (e.g. HAD in the absence of

Lack of common tools and shared culture, which impact on anticipation of needs and coordination (e.g., anticipation of HAD

SSIAD Nord Bassin: Getting a patient onto this path is complex.

leaves the teams suffering. Sometimes, private registered nurses

Sometimes, GP refuse requests, which blocks the process and

ask for help with pain management, but without the doctors'

prescriptions. Validating the GP for palliative care is one of the

difficulties encountered by professionals in the field in getting

SSIAD Nord Bassin: It might be a good idea to contact palliative

intervention. What's more, some patients have no GP and/or their

care before the GP, as it's very complicated to maintain a link

GPs are sometimes overwhelmed. "It's sometimes prehistoric

Taking the time to explain palliative care and deconstruct

Make a clear announcement of the situation to help manage it

Promoting communication between professionals to ensure a

Carry out a global assessment focused on the patient and share

DAC 33: There is a need for articulation between the palliative care pathway and the other players involved. There may be situations where palliative care coexists with other interventions,

involving players such as the DAC or other professionals, who

DAC 33: The referral process often seems exclusive. In complex situations, the link is made with the DAC, whereas for situations

care. It would be interesting to consider a more integrated

HAD, to offer more comprehensive support.

tool for requests could prove beneficial.

proximité), particularly in rural areas.

include palliative care coordination initiatives.

considered non-complex, patients are referred solely to palliative

approach, combining palliative care with other players, such as

SSIAD Nord Bassin: In a rural context, reporting on a common platform could greatly facilitate communication between the various players. The PAACO Globule system is used, but

exchanges by telephone and email are still frequent. The link to PAACO is not always operational, as many doctors do not use it. At present, requests can be made directly on PAACO, enabling a response and redirection to other teams. The idea of a centralized

GNA: For a patient without a general practitioner, the Territorial Professional Health Communities (CPTS) have a role to play.

EMSP Estey: Partnerships with CRTs and CPTSs deserve to be explored in greater depth and potentially included in the course.

DAC 33: It's important to note that CPTS health projects also

SSIAD Nord Bassin: Initiatives for the elderly, involving a coordinating doctor and a palliative care team, are being developed with the CRT (Centre de Ressources Territoriaux de

it with all players to avoid disruption to the patient's care

smooth palliative care process from the outset

(common tools, awareness-raising and training).

may be present simultaneously.

with GPs, especially when they refuse the mobile team's

presence, this raises logistical issues, particularly with

palliative care treatment and support off the ground.

enter PC

validation by the GP for SP).

what's going on in rural areas".

preconceived ideas

better

before return home).

patients and caregivers.

life I imagine, whereas each case is individual."

if... at the limit it would perhaps have seemed shocking or harsh to me. But the fact that

"Honestly, two-thirds of the time, I have an almost normal life (...) it's pains that have a rhythm

"Honestly, two-thirds of the time, I have an almost normal life (...) it's pains that have a rhythm

"I want things to go quickly", "I've been waiting a year for my death", "it's not easy for my loved ones

"At first, I was a little afraid of medication. "They explained it so well, saying it's a very small dose."

"I'm lucky enough, it has to be said, to have a small garden... When the weather's nice, I prune, plant

"I only ask my son and my neighbor to do my shopping (...) The rest, I wash myself in the shower,

without sitting down, I do my toilet. Well, it's not quick. I cook. I have friends over for lunch. I do the

cooking. I have a housekeeper (...) for two hours a week. That's more than enough for what I have in the

"We never saw the HAD doctor, but we could call him and get an answer. Well, I gave them a lot of

"The young man who brought me my oxygen was a darling. He brought my bottles in, took them out,

"Thank you Internet. Because at 10 o'clock at night when I'd finished, when he'd gone to bed, when it was quiet and all, I'd get on my computer and try to understand. So I found lots of sites, I read everything there was, lots of Canadian sites, I spent hours on the Internet, and I think there might be a way of getting information to families, without them having to spend hours on the Internet. So if there

"I'm happy with the comfort I was able to give my husband because he was at home. Right up to the last moment, I gave him what he wanted to eat. I gave him some wine because he liked wine, and I

Weekly team meetings and regular intra- and inter-team multidisciplinary exchanges

CAPalliatif: Teleconsultation is sometimes a useful tool for maintaining contact with patients, with tablets in some patients' homes. There are also informal practices, particularly in rural areas, where teams sometimes use WhatsApp to communicate

USP stay for caregiver respite (2 falls at patient's home)

"At first he said no, but then I told him I'm not going to make it, I

absolutely have to be able to reorganize myself, get help, etcetera,

"it was his choice to die at home (...) he chose what he wanted and

"They're a great team (...) Well, unfortunately it only lasted a month.

That's all. But, first of all, he went home as he wished and then in conditions that were, in a word, acceptable, as far as we could

asked us to help him because he couldn't see himself doing it

HAD - hospitalization at home / formidable team

Organization and coordination of conventional

Distribution of coordination and monitoring roles

acceptance

HAD - hospitalization at home / anticipate actions to be

"The loneliness, that's what was so heavy. Because when you're sick,

"Indeed, all the time it was getting into phase, the loneliness, it was

"Ah well, it's invasive, isn't it! You don't feel at home anymore, but

taken to alleviate loneliness and isolation

you're still cutting. There's family. But I'm alone."

"Because it took a long time to fall into place."

HAD - hospitalization at home / home invasion

Homecare undermined by lack of foresight

could prevent Marinette's son from becoming

could reduce the need for a DAC.

possible.

DAC 33: If HAD were referred earlier in the process, it

exhausted. It's possible that early HAD intervention

HAD Bagatelle: Communication between all partners is

essential to optimize care. All too often, these patients

even though a dramatic diagnosis has been made. It's

vital to involve everyone in the patient's life as much as

find themselves isolated on discharge from hospital,

Emergency/unanticipated hospitalization request

HAD Bagatelle: Marinette is our daily routine. What

complicates our intervention is that we are called in when her condition is already symptomatic. But HAD

should not be synonymous with emergency care. We

should all be co-actors in the patient's return home, but

at present, there's a lack of anticipation. It's crucial that

we are alerted as soon as she wishes to return home, so

that we can detect the first signs of decompensation and think about the appropriate care path from the

SSIAD Nord Bassin: We're used to receiving "Marinettes". In some cases, we're the ones who have to

call the HAD, but once again, there's a lack of foresight.

When the private nurses can no longer provide hygiene

and comfort care, they turn to us. We try to take over

what has been set up by the nurses and manage the

pain, but it becomes very complicated, both for our care

assistants and for the caregivers. We often feel that

we've arrived too late, and that we're helpless. We do our

best to organize the presence of two caregivers. The team benefits from training in palliative care, but the caregivers sometimes fear that they won't be able to

carry out the care properly. Ongoing support is needed.

They are present until the end, but the lack of

The lack of anticipation on discharge from hospital is

HAD - hospitalization at home / anticipate actions to be

"Before the person goes home, you have to take into account (...)

them, check all that out, so that you can immediately set up a

because when you're alone, things go round and round in your

head. It's not at all the same when you know you've got someone

coming... it's like little projects (...) It structures your week (...) you

really need to anticipate that (...) other than the presence of the

nurses, because they don't have the time, not that they wouldn't

Offering a respite stay at the start would be "fantastic", a

"Time to allow the family to adapt to home care, time to make sure

"It's a way of making sure that palliative care is put in place (...) it

time I spent on the phone, trying to find home help that I never

gives caregivers time to get organized. If you only knew how much

great opportunity to improve the palliative care

that caregivers have fully understood what awaits them..."

Anticipation of HAD before return home

experience.

network of visitors, as I call them, to avoid (...) moments of anxiety.

And these moments of anxiety were largely linked to solitude,

whether the person is married, whether they have children around

anticipation makes their work all the more difficult.

blatantly obvious here.

taken to alleviate loneliness

very, very, very burdensome."

what the hell!"

hospitalization or home hospitalization

accept. But they were really a great team."

"I was completely exhausted", "it was becoming impossible".

HAD - hospitalization at home / patient choice

and you'll be back, he said yes".

alone."

Anxiety/satisfaction

Food stop: « *shocking* »

despite this".

"Technically extraordinary", "totally effective in administering

it's an extraordinary painkiller, but really, you can't do better".

everything that was essential", "it works superbly, it soothes... well,

But the caregiver made enquiries and found that this

did not affect the patient: "in fact, he hasn't lost 1 gram

Application or revision of the personalized care plan

Protocole de Prescriptions Anticipées Personnalisées

Announcements of progress and test results are feared:

patients expect more support and relatives more clarity.

"It's that we don't know where we're really going (...) There are

moments when I'd like to know a little more about how... I know

more or less, but we haven't got into the details, how it's going to

end. Well, I think I'm going to stop breathing, or I'm going to be

stuck for breath. Is it the breath that's going to give out? Or is it, I

don't know, is it the heart that's going to stop? Do you know what I

Need for reassuring monitoring day and night

"at night, the girl, really, once, she was completely out of it".

Misunderstanding, need for more communication

« I had a bit of a problem (...) with the doctor and the nurse there

[Marie Galène], because I didn't understand why he didn't need to

be hydrated or fed. It was just inconceivable! So maybe there's

Caregiver does not feel supported by the team in place

« Everything rested more on my shoulders... Even for the death (...)

Even the nurse wasn't capable of making a decision. It's really

serious because I had to call the general practitioner and he said

yes, well then you call 15. But it wasn't up to me to call 15, it was up

"I was thinking this calendar, well this presentation [the route] is

families. For example, I would have liked to have been told that he

didn't understand it. Something like that (...) You said this word and

And that's why I wish someone had told me (...) that his disease was

wouldn't have gone home, and that's something I'm having trouble digesting, even almost a year later. And I don't think it's any harder,

« It's true that I guessed it, I wasn't specifically told... I figured it out

"But we're so hurt, we're so unwilling to face things, that indeed we

may take a long time to understand, but we have to insist!"

Anticipation of this phase, with more information

upstream, and potentially psychological support

Present the "timeline" of the palliative care journey

Generalization of bereavement follow-up actions

HAD Bagatelle: At present, we have few initiatives

concerning death and bereavement compared with

EMSP Estey. This is an area where action is essential.

There are simple things we can do, such as sending

support from start to finish.

letters or calling the psychologist, to ensure consistent

terminal. Because I would have stayed in hospital that night, I

anyway, because the next day, I knew it was terminal...".

for myself. »

I didn't understand what it was (...) And then around 11:30 pm, I woke up, I said to myself, but by the way, the word, so I went on the Internet... And I saw terminal COPD. And that's how I found out he was terminal. But for me, it wasn't terminal the next day, you see.

interesting. It would be nice if it were communicated to the

was terminally ill (...) I told you a few days ago, doctor, he has

cognitive problems and you said, I don't remember the term...
encephalopathy... Something like that (...) You said that word and I

to the doctor to do his job. » Mrs 2

Saying things, communicating more

something to be improved in terms of communication at that level.

Patient follow-up after death

"When my husband died, I wrote to them [the liberal nurses] to

Earlier psychological care for patients and caregivers

"Afterwards, I wondered if he shouldn't have had psychological

support beforehand, because he was asking himself so many

no choice and that... that doesn't stop the questions."

questions (...) even if intellectually, he had completely integrated the

fact that he was going to die and that he had to die and that he had

« (...) I had to fight to get him to agree to take him on, come what

may, because if he didn't I told him that in 2 months you'd have 2

patients on your hands (...) There comes a time when people who

suffer from severe cognitive disorders, not taking them on, is also a

form of non-assistance to a person in danger (...)....) perhaps there's

something to be reviewed in this area too, because here's the aspect

we're interested in, there's the medical aspect of course, but above all there's the psychological aspect, both for the patient and the

caregivers (...) because well, for 10 years, he kept telling me I'm going

to die, and then for the last 2 years, it wasn't I'm going to die, it was I

want to die. Well, you have to be able to cope! It's complicated! »

had died, etcetera. I didn't even get 1 SMS back, you see!"

thank them for their interventions and to tell them that my husband

Patients want to know what to expect

Evaluating the benefits of a sedation protocol

Close monitoring of clinical progress

The day after he was admitted to the USP for respite

back. But he told me so much, that I told him, well, stop your

"And he told me, you know, if I go to Saint-André, I won't be coming

nonsense, there's no reason to. You're going to Saint-André, and if

you don't like it, you can come back on Monday and I'll take you

home. And that's it. And that's how it went."

Condolences to loved ones

Bereavement counselling for relatives

care, the patient died.

and take cuttings. That's part of my job too. I take cuttings for other people."

"For me, it was a very positive experience, I needed it and it helped me."