



Negotiating the Care Maze in poetry:

The process of decision-making when a family member or friend needs full-time residential care

Acknowledgements

We wish to extend our heartfelt thanks to the individuals who shared their often painful stories of arranging care for a loved one for this study. They recounted emotionally and physically exhausting experiences, some of which had not yet come to an end, and as researchers we felt honoured to be able to capture them for this project.

Many of the participants told us they agreed to share their experience in the hope that it would make the experience of negotiating the care maze easier for others – we do too.

AUTHORS

Gayle Letherby
Oonagh Corrigan
Abbi Davies
Hannah Fletcher
Carly Guest
Rebecca Luff-Smith
Michelle Paul
Lucy Taylor



Introduction

The poems that make up this collection are excerpts of interviews given as part of a research study to uncover the lived experience of people arranging full-time, residential care for a friend or family member who can no longer be cared for in their own or another's home.

Our study, called *'Negotiating the Care Maze'*, was concerned with exploring how people navigate this journey from when they first began to realise that their relative may need residential care, to when a care place was secured, as well as subsequent events. We were particularly interested in understanding both the practical and emotional challenges our participants faced. In order to best elucidate these experiences, we used innovative auto/biographical methods.

A team of six Healthwatch Essex researchers received specialist training from independent consultant Professor Gayle Letherby and the subsequent study was jointly led by Gayle and Dr Oonagh Corrigan, Commissioning and Research Manager at Healthwatch Essex. The interviews covered everything from the financial implications to the importance of choice and information, as well as the sense of loss of identity often experienced by a person needing care. The main study report, *'Negotiating the Care Maze'*, can be found at www.healthwatchesessex.org.uk/our-reports.

The poems presented here are the words of those who were interviewed. The 12 interviews (six participants were each interviewed on two occasions) were transcribed and initially thematically analysed before being further analysed to reveal these poems. The poems were produced by reading through each interview transcript and highlighting each use of the first person 'I' and associated verb or seemingly important accompanying text. The run of words associated with the 'I' statements that are highlighted are an intuitive process, with the researcher judging what is important in understanding the interviewee's sense of self.

The second step involves cutting and pasting the highlighted phrases out of the transcript in the exact sequence that they occur originally in the interview, and placing them in separate lines, to form the lines of a poem. The same method is used to identify the 'he' and 'she' sentences so that the interviewee's perspective of their relative's experiences is also highlighted. The small differences in style and focus in the presentation of the poems reflects the individual choices made by each researcher regarding which aspects of an account to focus on; whether or not to draw on both interviews or only one, and whether to incorporate all 'I'/'he'/'she' statements or just some. Further development of the poems was undertaken to distil the key issues and concerns of the participant.

- 1** Thematic analysis "involves identifying key topics and patterns, regularities and contrasts in the material in order to create interpretive meaning." Edwards, R.E., and Weller, S. (2012)
- 2** Edwards, R.E., and Weller, S. (2012) Shifting analytic ontology: using I-poems in qualitative longitudinal research. *Qualitative Research* 12(2) 202-217



Joanna



Joanna's mother is 87 and her father is 90. Until February 2015 they lived independently in the house they had lived in for 50 years. Joanna's mother began to have problems with her memory and cognitive functioning about four years ago and dementia was diagnosed about three years ago. Joanna's mother's physical health also deteriorated and she suffered a cardiac incident and a number of falls.



Joanna's mother is currently in a dementia specialist facility, having been for a time in a general care home which was unable to fully cater to her needs. Prior to this, she was hospitalised abroad during a stay with Joanna's brother Adrian. The family considered a nursing home place near to where Adrian lived but decided against it, not least because of the poor conditions. Joanna's mother and father do not qualify for financial help for their care needs.



I, Joanna

I work in Chelmsford
I would call in two to three times a week

We were kind of waiting for something to happen
I needed to go in and do a lot of shopping and a lot of cooking
and a lot of . . .
I started doing the washing and I started doing the ironing . . .
I've had to do a number of things which I never, ever
expected to do

I had to insert a 'do not resuscitate' request into my mother's
notes with her GP
I've had to do all sorts of things that I never imagined that
I would have to do
There are things that are totally unexpected
I went out to buy my mother underwear
I was thinking . . .
I want my mother to look nice
I've never, ever expected . . .
I know that sounds a bit simplistic
I'm not sure that anybody could have helped

I said 'Okay'
I think that somebody had to actually stand there and say,
'Don't be so ridiculous. This isn't going to work.'

I think that my experience is different
I know some of my way around
I know people that I can ask

I'm just about holding things together
I've struggled with acknowledging that my mother has dementia
I just want to be knocked on the head and put in the compost
heap, please
I've had conversations with my husband
I don't want you to do anything
I want you to help me, a sort of Dignitas type thing.

She, Joanna's Mum

The following poem from an interview with Joanna focuses on her reflections of her mother's identity and experience.

She was an articulate, competent, confident woman
She developed signs of cognitive issues probably about four
years ago

She was still driving
She was still trying to do various things

She had a cardiac incident and needed quite a lot of support
She had atherosclerosis and needed stenting

She just took to her bed

She's down to six and a half stone

She said she felt safest in bed

She felt safest in bed
She was anxious when Dad went out
She was anxious around the house
She just couldn't cope and neither could Dad

She'll look at me and say, 'Have you come far?'

She sometimes can't remember his name

She fell out of bed three times that night and probably
had a stroke

She has carers that sit with her
She goes into other people's rooms

She needs reminding about eating

She's content
She's not anxious
She's not depressed
She's not aggressive

She has her hair done

Maggie



Maggie's mother was 91 when she was diagnosed with multiple myeloma (cancer of the bone marrow). This was in June 2013. She also had macular degeneration and was registered blind. Maggie's mother died in March 2014 aged 92. Nearing the end of her life and in hospital it was suggested that a nursing home would be the best place to care for her. The family agreed to this but knew that their mother would be reluctant and would rather return to her home in a sheltered housing facility. Mixed messages from medical staff upset and confused the family and delayed the application for funding support. Securing funding and finding a nursing home in a suitable location and condition was largely Maggie's responsibility. During the interviews Maggie stated several times that despite considering herself to be 'relatively switched on and articulate', she 'couldn't believe' how difficult the process of negotiating care was.



She, Maggie's mum

This poem from an interview with Maggie focuses on her mother's experience.

She was diagnosed with Multiple Myeloma
She's dancing with my son

She started
She couldn't

She'd gradually

She was very tough
She never wanted to know

She'd been in
She knew what she was signing up to

She knew that
She didn't want to talk about it

She was dying
She was still continent

She was an intelligent woman
She needed to be involved

She understood what he was saying
She didn't really understand

She had agreed
She was being fast-tracked

She said that she liked one of them
She was getting fast-track funding

She'd been up there to have tea with somebody
She will be paid for

She came to the area to be near us
She has great memories of it

She was a parcel
She'd have died in hospital

She wouldn't talk to them unless I was there
She couldn't understand what they were talking about

She wanted
She needed

She can't see anyway
She was saying 'What does that mean?'

She'd had the various assessments
'She's not getting better'

She was not a parcel
She used to go and have her nails done once a month

She was resigned to it by then
She had all her photographs

She had an awful lot of trust in me
She'd say

She felt
She trusted me

She had such complete trust in me
She knew

She trusted me
She was perfectly entitled to say that she wanted to go home

She needed
She wouldn't want us to

She found it distressing that I would have to
She did trust me

Angie



Angie's mother was diagnosed with vascular dementia about six years ago. Following a fall approximately a year and a half ago, it became impossible for her to live on her own. She was divorced from Angie's father (and her second husband was deceased), but Angie's father remained in contact to the extent that he visited her every day. Following her fall Angie's mother moved into Angie's father's house and eventually they moved together back into Angie's mother's bungalow. By this time Angie's father was providing 24-hour care and becoming very tired himself. Respite support financed by Social Services helped for a while but the rules around how this money could be spent seemed fairly inflexible. Angie herself suffers from multiple sclerosis which affected the support she could provide her parents.

Angie's 'I poem' powerfully demonstrates the confusion individuals can feel when trying to negotiate this maze-like process, combined with the associated distress and insecurity.



I, Angie

I can't remember exactly
I've developed a soft spot for her
I'm now understanding
I found that very difficult
I'm grateful that I had the opportunity to understand
It's something I've never considered before
I remember being extremely upset
I insisted on seeing the doctors
I wasn't going to let this go

I did understand on one hand
I was faced with the medical decisions as in between a rock and
a hard place
I find that so appalling
I think these unsavoury aspects are never discussed
I have never read anything or known anything about that at
this home

I don't know what the best solution is...it is so overwhelming
I was so muddled and I couldn't concentrate

I don't know and this is a question I'm scared to ask
I don't know what it means
Both my father and I were extremely upset

I don't know
I can't remember
I don't like that
I didn't have the right to put her there

I don't think so
I'm not sure

I've no idea
I agree but I've just noticed . . .
I don't know

I think they are very dedicated staff
I have a big fear
I thought that was, actually, shocking
I didn't even know who she was either
I don't know what they might think
I don't know about the care home
I just think it's a very sad situation and nothing can take it away
I'm taking her out of here . . .

Mark



Mark describes his wife, Paula, as a chronic alcoholic. Paula is 53 years of age and she and Mark have been together for 10 years or so. Mark says that from what he can gather from family and friends, Paula has been an alcoholic for many, many years. Mark had previously initiated divorce proceedings, but stalled when this led to Paula drinking even more. Paula was sectioned under the Mental Health Act three times and eventually put under a Deprivation of Liberty Order. In December 2014, Mark found an appropriate care home in the South West of England and Paula accepted a placement there.



Things are much better now. Paula is alcohol free, although she suffers some permanent brain damage from her drinking. Mark is now worried that Paula is 'institutionalised' and is concerned about how she might be best integrated back into everyday life.

The following two poems (one from each interview) highlight Mark's representation of his wife's experience.

She, Mark's Wife. Part 1

She's 53 years of age and we've been together now for about
10 years or so.

She's been an alcoholic for many, many years.

She was absolutely hopeless to live with

She was doing crazy things

She nearly set the block on fire

She threw her empty vodka bottles out of that window behind
you to your left

She was laid sprawled on this floor here

She accused me of

She was attacked down the town and robbed

She gave money away to people

She'd already been pulled in by the police under Section 136

She was, first of all, placed under Section 2 of the Mental Health
Act and then Section 3

She appealed and the appeal was successful . . .

She, Mark's Wife. Part 2

She is a likeable person

She's done it before

She's still been banged up

She's got a lovely sea view

She will look back upon it as a horrific experience

She's been in a protected environment for all that time

She used to watch Jeremy Kyle and stuff like that

She loves horses

'She's got to have things to do'

She said, 'I just let it go over my head. I just sit there'

She does a bit of meditation

She does a bit of exercise in her room

She does word search books

She looks great

She looks fantastic

She's not had a drink for a long period of time

She was cooking and shopping for the community room and the
other residents

She was just living her life as normal

She was doing okay

She had an advocate when she was under Section
She's getting a little bit confused there
She's being a bit obtuse there
She gets herself showered and dressed, does her room, cleans
herself up, does everything, and gets down for breakfast.
'She is generally happy to follow her own morning routine with
the assistance of staff. No concerns'

She's under the NHS
She's had an MCA
She's got the capacity
She doesn't forget what she's done in the day
She writes it down as it happens

She said, 'Oh, I haven't done you anything.' I couldn't believe it
She looks totally different
She does look well, I've got to say

I, Mark. Part 1

I started divorce proceedings against her
I found another person's clothing in my wardrobe
I came in she was laid sprawled on this floor here
I, myself, was interviewed by the police
I was at work at the time
I think this was done three times

I was sometimes allowed in at the ward meetings, sometimes not
I didn't want her to be able to have an appeal against it
I was her representative at the time
I'd told the services that there's no way that I wanted her back
here to live with me in the state she was in

I found a care home on the web, and I took her down to this place
I can't remember the exact date
I took her down there, dropped her off

I didn't want to divorce her, but there was no option
I saw her through 10 separate detoxes and rehabs

I mean, she'd give them £50 for a bottle of vodka or something
like that

I said she had to stop
I had trouble with the tenants in the flat
I realised she drank, but it deteriorated

I can't keep her banged up down there indefinitely, because
that's not on either
I wouldn't have her back here
I wasn't present when the assessment took place
I've not been told how much it was, and the commissioners
wouldn't agree it
I visited a brain damage specialist place
I took her up there

I don't know

I've been going down and visiting her regularly
I'm telling them that that's what's got to happen
I'm not driving 250 miles there and 250 miles back

I've told her innumerable times that I've done as much as I can
for her
I can do no more

I wondered what he was talking about. 'Navigate me through it?
I've actually been round in a complete circuit and come back to
the person I started with
I belong to care groups as well, is so small that there's just
nothing they can do

I think they've probably failed, but I've not pushed it
I felt that they should allow her to go out by herself, and they
started off
I moaned about it that much that they knew when I was
coming down to take her out

I've been there myself and seen the place
I ignored all that. I just left her there
I had showed her the brochure a couple of times, and the
brochure puts quite a bit of spin on the place

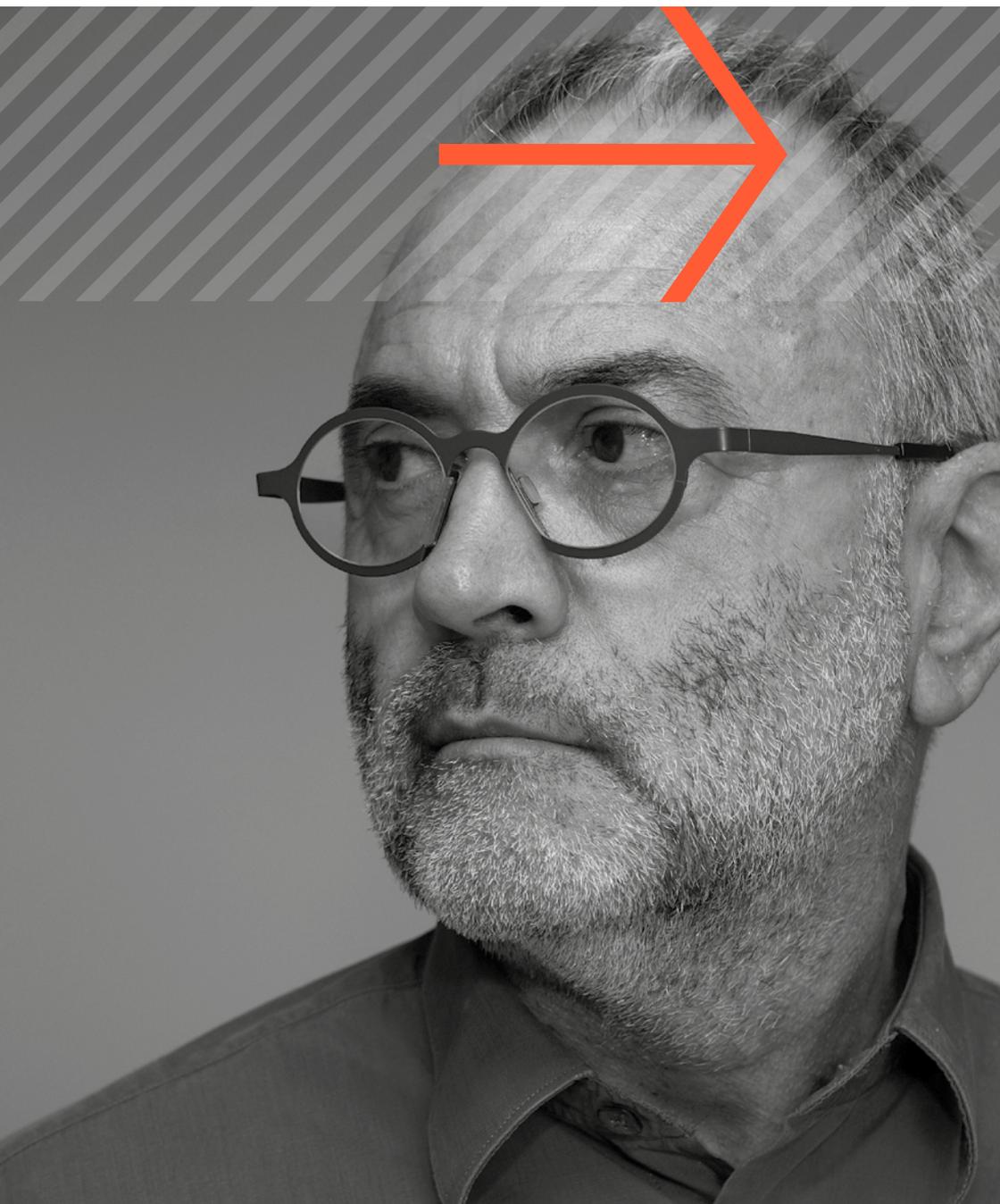
I took her down there, and she was assessed the first time on
23rd April
I got the forms for the Mental Capacity Assessment
I knew what they were going to say to her

I want them to establish the fact that she's able to get out by herself
I'm bloody worried
I would sooner she stays there
I can't leave her there
I said, 'I've done all I can for you.'
I can't do no more
I don't want to divorce her
I can't go through that again
I've been living by myself, effectively, and doing my own thing
for the best part of 18 months
I want this period of time where the two things can happen
I want her to do things by herself
I want her to be involved
'I want her to have some counselling, to improve her
emotional strength.'
'I want you to facilitate Paula doing ...'

I'm very - I won't say upset, because at the end of the day it
has worked for her

I'm finished ...

Phil





Phil's father is 84 and has been married to Phil's mum for 59 years. Phil's dad's condition began to deteriorate about 18 months to two years after diagnosis and caring for him began to take its 'toll' on Phil's mum. Phil's cousin moved in to help, but Phil's dad soon became increasingly vague and began to develop 'bizarre habits'. The family discussed the possibility of a live-in carer and modifications to the family home, but further deterioration made a care home the only option. After a fairly extensive search Phil and his siblings found a couple of care homes they were comfortable with. The whole experience has had a significant financial impact on the family, so much so that Phil's mother may have to move to a smaller property fairly shortly.

The first of Phil's poems focusses on his experience of arranging care for his father, and the second shares his feelings and perceptions about his father.

I, Phil (from interview two)

I got a little bit confused with all that
I'm going around and around in circles
I mean, emotionally it was, yes, quite tough
I think he was probably struggling to make sense of what was
going on
I could envisage a situation whereby we would want to put him
into a home but they wouldn't take him because we didn't
have power of attorney
I should have known better, really, in that situation, but there we go
I think we pulled out all the stops for him not to have to go into
a home
I think we saw the impact it was having on mum
In the end, I don't think there was any option
I look at him now in the home and I think, he's got other stimuli
there, there are other people he can talk to, and they've
got lots of good staff there
I mean, emotionally it's not great
I think it's when your loved one is protesting against what you're
doing that you'd have problems
I think my mum and my sister find it a bit harder, to be honest
I think maybe I've just become a little bit hardened to it
I don't know

He, Phil's father (from interview one)

He was brought up in the East End
He left school at 14
He has always been a very strong character - never had any
self-doubt
He has always ruled the roost - what he says goes
Although he's always been firm, he has always been reasonable
He has been a good father

"He was having problems with his comprehension and with
his memory"

When he was driving he was having difficulty with directions
He was starting to get a bit confused in the evening
He was getting up early in the morning, like 3 am

He never asked about it.
Maybe his brain power or his cognitive functions had deteriorated
to a certain extent by that stage
He never once asked and he never has since

He was told he couldn't drive
He thought it was going to be a temporary measure
He was still drinking heavily and smoking
He was always only ever going to do what he wanted to do

He started to forget how to smoke
He was starting to put a fork in his mouth and trying to smoke that
He was on Diazepam
Because he was getting agitated
But then he'd be quite aggressive when he woke up
There were times when he wouldn't take his tablets
He always did what he wanted to do

He went in in January
He's got a care plan there which they ask us to review regularly
He has never asked to come home
That's not true actually, in this past week he said "Are we
going home?"
He was wandering about quite a lot at first
He does seem to be a lot more settled
He still recognises us when we go in - doesn't always get
our names right
His short term memory is shot to pieces
His long term memory . . .
He might say "oh, how is Terry?" - Terry was his brother who
passed away five years ago
He is eating well
He has put on a bit of weight
His mobility is better

Dad is not going to get any better
I mean, I think in his own mind, he is actually okay.
We say "He's in his own little world".

Jayne





In 2011, Jayne's father was diagnosed with vascular dementia. Jayne's mother, who is 83, was finding it increasingly hard to cope with his care, and so Jayne's parents moved to Essex in 2014 so that she could help support them. Soon after the move, the family reached crisis point, as Jayne's father's mobility decreased and he was admitted to hospital following several falls. Jayne and her mother had been considering options for her father such as part-time or live-in care, but at this point it became obvious that nursing home care was required. However, the hospital wanted to discharge Jayne's father before the family had found a placement for him.



Jayne talked about the rush to find a care placement for her father, and wondered how this difficult process might be even harder for someone who did not have the knowledge about Care Quality Commission reports, and so on. She also found the Alzheimer's Society very helpful.

Jayne's father died in 2014. This poem highlights Jayne's experience.



I, Jayne

I don't know what we're going to do
I can't get an overnight carer in at short notice
I don't know how it works
I'd done quite a bit of research
I was also able to look up all the CQC reports for all the homes
I ruled out one or two without even going
I roped my brother in
I'd got the website up . . .
I thought 'We're going to have to try and explain this to dad'

I burst into tears

I wanted to get Mum some support
I think, possibly, it would be better if there was a helpline for carers
of people with dementia
I was trying to find out what was happening
I contacted the Alzheimer's Association
I was trying to find overnight care
I felt so helpless a lot of the time
I couldn't go to appointments
I couldn't see for myself what was happening

I'm like that
I'm curious
I want to understand
I'd done alright until quite near the end
I got a bit upset

Previous research has indicated that illness, particularly degenerative conditions, can cause a loss of identity. This identity loss is related to both our understanding of ourselves and our memories and so forth, as well as in our relation to other people, meaning that other people increasingly lose their ability to recognise us in our unique character (Gillies B. & Johnston G., 2004). This certainly chimes with how our respondents tended to speak of the change in their loved ones' identities. They wanted us to know something of the identity of the person who needed care and to give a holistic account of the person because, for many, including Jayne, they felt the illness their loved one was experiencing or had experienced had diminished or even replaced their individual identity. This excerpt from Jayne's 'He' poem nicely captures the wholeness of her father's identity:

He, Jayne's dad

He was born in Derbyshire
He loved the countryside
He hated towns and cities
He always referred to London as 'the smoke'
He loved going out on walks
He didn't learn a great deal at school

He started in a draughtsman's office

He did years and years at night school
He went on from draughtsman to mechanical engineer
He was in the Air Training Corps
He loves aeroplanes and things
He got his glider's pilot licence
He loved swimming
He passed that onto me and my brother
He was in the care home

Dad had actually got out of bed and started rearranging the
furniture

He'd moved this, that and the other
He was camping
He was on the floor 'Got to make a fire'

He's got dementia.
He had a will of steel
Dad was at the stage where he didn't say an awful lot
Dad's head popped up and he said 'It was a Polish chap that taught
me to fish'
He said 'They're all barmy in here, you know'
He did not like the fact that people were following him
He didn't understand it was because he was at high risk of falling
He was very independent, did not want to ask help
He would never use the help button in hospital
He would just get up and go
He even worked out that when he stepped on one of these mats,
somebody would come
He was still quite devious amongst all the other jumble of things

He just wasn't safe on his feet
He had a dog, it was a white German Shepherd
He got into trouble quite a lot with his mum

He was taken into hospital via the ambulance
He's lost a lot of sight in his eye

He'd got to the stage, by then, where he couldn't concentrate
He couldn't take the words in
He went round the country to shooting tournaments

He said that it's the shooting that really did for my ears
He got old
He was an avid reader
He'd get books every three weeks from the library
He couldn't read any more
He couldn't take the words in and process them

He wouldn't have been able to go anywhere on his own
He didn't say an awful lot.



References

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