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Letter to the editor

In reply to: Helmich and Bloem (2020) “The Impact of the COVID-19 Pandemic on Parkinson’s Disease: Hidden Sorrows and Emerging Opportunities”

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Dear Sirs,

We read with interest the paper by Helmich and Bloem outlining the Hidden Sorrows and Emerging Opportunities that the COVID-19 pandemic may bring to the Parkinson’s population [1]. As we are navigating our way through the complexity of providing support to people with Parkinson’s who are self-isolating, we find that our experience resonates with what the authors describe. However, an additional Hidden Sorrow is the impact on caregivers, and the relationship between them and those they care for. We present 3 vignettes (from just one day of community Parkinson’s nurse home visits) that illustrate this important, and yet easy to overlook, issue:

Case 1: Mr. N, 77 years old, has had Parkinson’s disease dementia for a few years. He is cared for by his wife at home, and has been having regular respite breaks in a local nursing home. The care home is not accepting respite admissions currently due to managing their risk of COVID-19. His wife has friends that would normally sit with her husband whilst she goes to the shops or hairdressers; they are

no longer allowed to visit. The Parkinson’s groups they both attend in the city have shut for the time being, although one is offering a monthly video meeting. Mrs. N did ‘attend’ a meeting, but her husband nearly fell over during the meeting and so she is not sure if she will attend the next. Mrs. N tells me that she is struggling with her patience and feels guilty that she is resentful that she can’t leave the house. She tells me that being with her husband 24 hours a day has brought it home to her that she won’t be able to cope once the illness progresses. Mrs. N is a talkative lady and Mr. N rarely initiates conversation these days due to word finding difficulties. The silence in the house upsets her. She is considering whether, once the care homes open again to admissions, her husband would be better off living there on a permanent basis. These thoughts, once again, compound her guilt. We agree together that an immediate referral to Adult Social Care would be appropriate so that more practical support can be offered to them both.

Case 2: My next visit is to Mr. P, 69 years old, who is entering a more complex phase of his condition and is having significant motor fluctuations. He experiences anxiety most days and this has increased recently due

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56 to his worries about contracting COVID-19. Due to
57 his asthma and Parkinson's, he is self-isolating with
58 his wife at home. His wife is upstairs when I arrive
59 but later joins us. She sits at the table behind her hus-
60 band's chair. Mrs. P looks irritated and exhausted,
61 and shakes her head when her husband speaks. I ask
62 her if she is okay. She tells she is frustrated that she
63 has to self-isolate due to her husband having Parkin-
64 son's whilst she is perfectly healthy. Mrs. P tells me
65 she feels guilty for thinking like this and is aware
66 that feelings of resentment are rising. She says she
67 is becoming more stressed due to their increasing
68 arguments and her husband's inflexible thinking. She
69 always knew he was anxious, but hadn't appreciated
70 the extent of it, as pre-lockdown she was out of the
71 house for many hours in the day. She tells me that she
72 can't wait to get out of the house when the restrictions
73 are eased so that she can have time by herself. Mr. P
74 thinks it will be years before he has the confidence to
75 leave the house again, and that she will be going out
76 alone. A referral to psychological services is offered
77 to Mr. P to address his anxiety; he declines at this
78 time. However, his wife agrees that she will contact
79 the local care advisor from Parkinson's UK for some
80 advice for herself. A small adjustment is made to
81 Mr. P's medication regime to improve wearing off.

82 **Case 3:** My last visit of the day is to a 65-year-old
83 man with Parkinson's whose wife recently died. He
84 wasn't able to be with his wife when she died due to
85 COVID-19 restrictions, or attend her funeral. He now
86 has visual hallucinations of his wife in his house. His
87 daughter now lives at the house and reassures him
88 often, but is coping herself with feelings of bereave-
89 ment. She says that repeatedly telling her father that
90 her mother has died and that the hallucinations are not
91 real is becoming difficult for them both. His daugh-
92 ter would like to have some help in the day from a
93 care agency but they are currently not taking on new
clients due to worries over COVID-19. We agree that

94 talking to a local bereavement service may be helpful
95 for the family, so I leave them with that number. I
96 also prescribe a medication that will hopefully help
97 the hallucinations. As I am leaving, and away from
98 her father, she confides in me that she would like to
99 move out again, but will stay for as long as she can.

100 The role of caregivers in contributing to patient
101 wellbeing is well established, as are the importance
102 and challenges of recognising, evaluating and sup-
103 porting carer strain [2]. With most clinic assessments
104 currently being conducted remotely, opportunity for
105 caregiver input, or checking in with the caregiver sep-
106 arate from the patient are limited. Carers are no longer
107 able to access their existing support systems. As care
108 providers, we need to develop processes for evaluat-
109 ing carer strain within our new framework of working,
110 understanding that we may not have usual resources
111 at our disposal to mitigate and support. As illustrated
112 by these vignettes, community Parkinson's nurses can
113 play a critical role in identifying the issue, evaluating
114 its severity and likely consequences, and implement-
115 ing solutions. Parkinson's nurses are a vital spoke in
116 the integrated model of care we deliver to our commu-
117 nity of people with Parkinson's and their loved ones,
118 not only for their specialist Parkinson's knowledge,
119 but also for their links within the interdisciplinary
120 team and broader community.

121 CONFLICT OF INTEREST

122 The authors have no conflict of interest to report.

123 REFERENCES

- 124 [1] Helmich RC, Bloem BR (2020) The impact of the COVID-
125 19 pandemic on Parkinson's disease: Hidden sorrows and
126 emerging opportunities. *J Parkinsons Dis* **10**, 351-354.
127 [2] Mosley PE, Moodie R, Dissanayaka N (2017) Caregiver bur-
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