"EASL Clinical Practice Guidelines: The Diagnosis and management of patients with Primary Biliary Cholangitis"

In lay terms: what does it mean for the patient?

The new EASL (European Association for Study of the Liver) Guidelines on the treatment of Primary Biliary Cholangitis (PBC) were announced at the EASL International Liver Congress in Amsterdam in April, 2017. The first revision of the guidelines since 2008, they aim to provide clinicians with clarity in treatment pathways, symptom management and best practice for the disease.

However, although the guidelines are undoubtedly a very positive step forward in the management of PBC, they are, as noted in their introduction, there to 'provide a framework to help *clinicians* to diagnose and effectively manage patients with PBC.'

Here at the PBC Foundation we believe that it is crucial that *patients,* who after all live with the consequences of any changes, and whether or not the guidelines are implemented in practice, are also made aware of the guidelines, understand the content and how they can best utilise them to optimise their treatment and prognosis.

Collette Thain MBE, CEO of the PBC Foundation, has this to say on the guidelines. 'These guidelines are significant for a number of reasons. They are the first EASL guidelines that have a contribution from the patient voice. They are also the first guidelines, we are aware of, to recommend each and every single patient with PBC be put in touch with a patient support organisation. Finally, as an organisation we encounter and support too many patients who are not experiencing best practice, which can be anything from unnecessary liver biopsy to under-dosing of UCDA. These guidelines can give the patient the support they need written in black and white to take to their clinician and ask for best practice when it comes to their individual care. These guidelines aren't the view of one person, or a patient support group: they are the views of an entire community, with their roots based in scientific data and evidence-based medicine. Our duty now is to ensure everyone who will benefit from the guidelines has an opportunity to know their content.'

Hepatologist and PBC specialist Professor David Jones of Newcastle University agrees:

'We should now be looking at how to take the guidelines and reach out to those who need them the most – that is the non-specialist clinicians, GP's and, of course, the patients. I am especially keen on empowering patients to 'own' their condition and open conversations with their clinicians about their treatment, referencing the guidelines if necessary.

'Overall, clarity of messages and ongoing education is key to ensuring that the impact of the guidelines is maximised and converted into high quality patient care'. So here, health writer Isla Whitcroft, Professor of Hepatology David Jones and patient advocate Robert Mitchell-Thain have produced a patient guide to ensure that, by utilising the EASL Guidelines, every PBC patient receives the optimum treatment for their condition, no matter where or by whom they are treated.

At 28 pages long, the guidelines may appear complex so we have summarised the guidelines in this stand-alone document specifically for the patient community to better understand the recommendations, what they mean for patients in everyday life and their care pathway in partnership with their clinicians. Essentially, from a patient perspective they can be divided into four sections.

Diagnosis and Assessment.

Treatment

Living with PBC

Watching PBC

We have also included useful questions throughout the sections for you to ask your doctor if you feel that your current treatment is not in line with the standards set by the guidelines.

Guidelines 1 – 18
DIAGNOSING AND ASSESSING PBC

'Once it is diagnosed, PBC is a very treatable disease,' says Professor Jones. 'Therefore, it is extremely important that a diagnosis is made as soon as possible but with minimum discomfort to the patient.'

Most cases of PBC can be diagnosed with a combination of blood liver (LFT) tests and the AMA test. Sometimes an equivalent of the AMA test will be carried out to look for different types of antibodies but that will make no difference to your overall diagnosis or prognosis. The guidelines make it very clear that liver biopsy, which carries a risk of bleeding and other side effects, should not be used as a diagnostic tool expect except in a very few cases (see later).

'Unfortunately, liver biopsy has been offered far too often, and incorrectly as a method of diagnosis in the past,' explains Professor Jones. 'In fact, in around 90% of cases, AMA and LFT tests together can provide a definite diagnosis of PBC.

'Crucially, if you have had AMA and LFT (usually Alk Phos) tests which confirm you have PBC you do *not* need usually a liver biopsy for diagnostic purposes. Sometimes a biopsy will help with diagnosis and management but your doctor should be able to explain why this is the case, specifically.'

QUESTION TO ASK YOUR DOCTOR.
My PBC has already been diagnosed with liver blood and AMA tests and the EASL Guidelines say that this is sufficient confirmation that I have the disease. Please can you explain why you are also offering me a biopsy?

Patient tip from the Foundation:

If a doctor is considering a medical procedure, any procedure, the first questions we hope that go through a patients mind would be:

1) What is it we are trying to find out?
2) Why is that information helpful?
3) Is there a better way to find that information?

Using these questions to inform your decisions will help you make the best decisions for your own care. It can also help the NHS in terms of fewer unnecessary procedures, hence saving money too.

The key word in the suggestion above is "offering". You are not obliged to accept the biopsy. You can refuse if you feel it is not the best way forward for you. Guideline 9 specifically recommends against biopsy in the circumstances outlined above. Hopefully, the questions above will help you make the best decision for you.

Once your PBC has been confirmed, the guidelines recommend that you should have an ultrasound scan of the liver in order to exclude other liver diseases. As well as the ultrasound scan, a minority of patients may need to undergo an MRI scan for disease stratification purposes but the majority of patients will not fall into this category.

'Essentially if you are not offered an MRI scan, then this is not a cause for concern,' says Professor Jones.

QUESTION TO ASK YOUR DOCTOR.
I have been diagnosed with PBC. The guidelines say that I should have an ultrasound scan of my liver to rule out any other liver conditions and I would like to have this carried out.

Patient tip:

It may feel bold to ask such a question but it may be entirely necessary. Gone are the days when medicine was practised *at* or *to* patients. In best practice, medicine is now very much practised **with** patients. If you feel you need more confidence, be sure to write down your questions in advance and take someone with you to ensure you have every question answered and to jot down those answers.

The Guidelines clarify that, if your blood tests are showing a potential positive for PBC but you have no PBC-specific antibodies it is still possible that you have PBC**.** Around 10% of patients fall into this category. To formally diagnose PBC, another diagnostic tool is needed which, in this case, is a liver biopsy. This is one of the few occasions you might need a liver biopsy for diagnosis. You may be offered a biopsy later on in your disease journey but that is for different reasons (see Treatment section).

The guidelines note that in some cases, a test result will show an AMA positive result whilst the liver blood test comes back as negative.

'Sometimes people with another condition will have a blood test which shows that they carry the AMA for PBC, whilst a liver blood test will be returned as negative,' explains Professor Jones. 'The guidelines make this clear that in this case you do not have PBC. This means that you do not have to declare the AMA test result to anyone including insurance companies or any other official body.

'You certainly do not need a liver biopsy to rule out PBC in this instance. However, there is a slight chance that you may go on to develop PBC in the future and the EASL Guidelines recommend following up with the usual blood liver tests every year just to be sure.'

QUESTION TO ASK YOUR DOCTOR:
I carry AMA antibodies but I don't have PBC. I would still like to have a liver biochemistry test every year just to check I have not developed the disease.

Patient tip:
This would make absolute sense in terms of minimising any risk to the patient later in life. As highlighted above, the earlier in the disease journey that a PBC patient is diagnosed, the better. This precautionary strategy would ensure that changes are picked up as early as possible. At this juncture, PBC would not be something to worry about as, in most cases, PBC does not develop.

According to the guidelines, every patient should be assessed for their risk of developing complications of PBC using a combination of non-invasive tests (such as bilirubin, alkaline phosphatase, AST, albumin, platelet count, and elastography) and a risk score assessment to establish baseline for subsequent follow ups. The guidelines note that particular attention should be paid to assessing younger patients as they sometimes have a more aggressive form of the disease.

'The same liver biochemistry tests that are used in diagnosis can be used to assess progress of the disease,' says Professor Jones. 'However, AMA results do not indicate disease progression or remission in any way. In fact, once they have been used for diagnosis they have little relevance for the stratification of the disease.'

QUESTION TO ASK YOUR DOCTOR:
I have been diagnosed with PBC. Have I been assessed for risk of complications and is there a baseline reading for my bilirubin and alkaline phosphatase levels, AST, albumin, platelet count? Could I have a risk score assessment (such as the GLOBE and UK-PBC score)?

Patient tip:
Upon diagnosis, you should have a record of your liver test results. Your baseline results are the first set you have upon diagnosis. Using the Foundation app, or just a pad and paper, keep a record of your results in subsequent tests.

Your risk score isn't necessarily permanent: things such as your response to treatment can have an impact upon your risk score. Risk scores such as the UK-PBC Score and the Global PBC Score estimate your risk of damage progression and not necessarily risk of complications. They are also very useful for measuring the benefit you are gaining from the treatment.

The guidelines clarify that if, after one year of treatment, you have responded well to Urso then you are an 'Urso Responder' and your transplant-free survival rate is normal compared to the general population.

The same goes for your chances of contracting any PBC related diseases. If you have not responded to Urso sufficiently within one year you may need further treatment (see Treatment). If you are in this group, then it is important to continue taking Urso as even if you haven't seen the level of benefit you and your doctors would like you will still be getting some benefit.

According to the guidelines, an Urso Responder, for the purposes of not needing second line therapy, is someone who has reached a level of less than 200 for Alkaline Phosphates levels and 17μmol/L or 1mg/dl for Bilirubin levels by one year after starting treatment.

QUESTION TO ASK YOUR DOCTOR:
Am I an Urso responder?

Patient tip:
Urso response isn't quite as simple as a one or a zero. There is a spectrum of Urso response, and each case must be taken on its own merits. If you are not an Urso responder, this just means that you are at higher risk of progression. Now, more than ever, this higher risk is managed more closely with improved results.

If you are an Urso responder, then that, too, will inform you care pathway and ensure you receive the appropriate level of care for your condition. This pathway, whilst still being monitored and medicated for all of your life, involves much less risk of progression.

During your diagnostic journey, your tests or risk score assessment may show that you may have some liver damage such as fibrosis or cirrhosis. This can be diagnosed by a Fibroscan, ELF blood tests or a blood test and risk screening system. You do not need a biopsy to diagnose cirrhosis.

QUESTION TO ASK YOUR DOCTOR:
Do you think I may have liver damage? If so can I be offered a fibroscan, ELF's or a risk screening to diagnose?

If you think I have cirrhosis can you explain why you are offering me a liver biopsy before I have had risk screening, and ELF test or a fibroscan?

Patient tip:
It is really important to remember that there are three aspects to PBC: symptoms, liver biochemistry (liver tests) and histological staging (cell change or damage within the liver). All three aspects need to be monitored to differing degrees throughout your PBC journey. As an active participant in your own care, you have every right to know where your liver is in terms of any damage to the cells within.

TREATMENT

'There are two main treatment aims for PBC, each as important as the other,' says Professor Jones. 'The first is to reduce the risk of progression to cirrhosis, the second is to reduce the effect of the symptoms.

Guidelines 19 - 25

The guidelines confirm that everyone who is diagnosed with PBC should be treated with Urso with the correct dosage being 13-15 mg/day per kilo of weight and a close eye should always be kept on your weight in case it fluctuates.

'There are no ifs or buts about this, Urso should be the first line treatment for everyone,' says Professor Jones. 'In addition, studies have shown that patients who are dosed correctly according to weight do far better than those who are under dosed, so it is crucial that your weight is monitored regularly and your Urso dose adjusted accordingly. It is unfortunate that is still not being done in many cases.

'If you are an Urso responder you must continue on Urso for the rest of your life. If your condition has improved it is because the Urso is working and if you stop taking the Urso your condition will deteriorate.

'You may find that taking several tablets of Urso every day is difficult to maintain. If this is the case ask your doctor if you can be moved onto a higher, one dose version.'

QUESTION TO ASK YOUR DOCTOR:
Is my Urso being prescribed according to my weight at between 13- 15/mg/kg of my weight per day?

I wish to have a regular weight and dosage check added to my treatment regimen.

I am struggling with multiple tablets. Am I suitable for a higher dose, once a day dosing version of Urso?

Patient tip:

PBC Foundation surveys in 2017, whilst unpublished, showed that much work needs to be done to ensure every single patient is dosed correctly with their Urso. The preliminary results tell us that 11% of PBC patients are not taking Urso at all. Considering those taking Urso, when directly measuring their dose to their weight as declared, 49% of participants were taking less than the EASL recommended dose per day. We cannot emphasise enough the correlation between proper dosing of Urso, Urso response, and life expectancy. Urso is available in a number of options, including 150mg, 250mg, 300mg and 500mg. In a small number of patients, it is necessary to take very slightly over the recommended dose because of the parameters of available medicines.

'If you are not an Urso responder than you should be considered for further treatment. Obeticholic Acid (OCA) can improve blood levels in 'non responders', it has been licensed for use in many countries, including the UK, Canada, USA, and Germany, and is available on prescription.

'Obeticholic Acid should be given in combination with Urso unless you are intolerant to Urso in which case you can take it as a solo therapy.' The guidelines are very clear about the dosage of OCA to be given to patients.

QUESTION TO ASK YOUR DOCTOR:
I am an Urso non-responder. Can I be considered for Obeticholic Acid?

Patient tip:

Obeticholic Acid is the only licensed second line therapy for PBC. There is increased risk of itch as a symptom but this is reasonably well managed in most cases, with rifampicin being the preferred medication used for itch. In clinical trials, OCA was shown to improve liver biochemistry in the vast majority (87%) of cases and in the stringent classifications within the studies, it was found to help almost 50% of patients in the three measurable incorporated into the POISE study. If Obeticholic Acid is an option for you to consider but you have concerns, please contact the Foundation directly so we can assist you in this part of your journey.

Your clinician may wish to consider fibrates or budesonide, neither of which are licensed for PBC, as a second line treatment for your PBC. It is important to know that the EASL guidelines states that a recommendation for such therapy cannot be made. This may change in the future, but as of 2017 this is the current status.

QUESTION TO ASK YOUR DOCTOR:
I am not intolerant to Urso. Can you explain why you are stopping my Urso treatment now I am on Obeticholic Acid?

Patient tip:

Obeticholic Acid has been recommended as a monotherapy **only** for patients who are intolerant of Urso. The EASL guideline recommends combined therapy in all other cases. It may be helpful to you to be aware of this before your conversation with your clinician.

Pregnancy and PBC
The guidelines provide reassurance that Urso does not affect your chances of getting pregnant, nor will it harm your pregnancy in any way.

'A close eye should be kept on weight fluctuation throughout pregnancy and dosage adjusted according to any body weight gain - not including baby weight,' confirms Professor Jones.

'It is extremely rare for cirrhosis to be present in a woman of child bearing age. However, if this is the case, then special monitoring will be required throughout pregnancy.'

PBC/AIH Overlap

The Guidelines note that PBC can occur alongside another auto immune condition (an overlap) the most common example being Autoimmune Hepatitis (AIH), which is treated with immunosuppression and steroids. AIH is usually indicated by a high ALT and IGG liver blood reading.

'Although AIH overlap with PBC does exist, it is also over diagnosed,' says Professor Jones. 'It is important to confirm that you do have AIH before you are started on treatment as some types of steroids, for example prednisolone, can substantially decrease your quality of life.

'If there is any doubt about diagnosis, a liver biopsy will help to confirm or rule out AIH. Although biopsy carries a risk of bleeding, in this case I believe this risk is worth it as it can spare you a lifetime of extra medication if you have been wrongly diagnosed with AIH.'

QUESTION FOR YOUR DOCTOR:
You say I have AIH (or PBC/AIH Overlap) but can you explain exactly how you have come to this conclusion? Is there any doubt in this conclusion and should I be considered for a biopsy to confirm or rule out AIH?

Patient tip:

PBC is a condition that has a very successful diagnostic tool in AMA, which is present in approximately 95% of PBC patients. AIH (and thus PBC/AIH overlap) has no such diagnostic tool currently and so is dependent on liver biopsy for diagnosis. There are liver biochemistry tests which are suggestive of AIH as a possibility but they are still not diagnostic.

The treatment of AIH also doesn't benefit from simple, clear guidelines such as those for PBC. Treatment of AIH is not consistent, either within the disease or within the community, and may need to be tweaked as changes happen to the patient. These tweaks in care are very much dependent on the expertise of the clinician.

LIVING WITH PBC

'Some doctors believe that it is more important to reduce the risk of cirrhosis than it is to treat the symptoms of PBC,' says Professor Jones.

'The Guidelines remind us that the symptoms of PBC are a major part of the disease and therefore treating the symptoms of PBC is as important as reducing the risk of cirrhosis.'

QUESTION FOR YOUR DOCTOR:
Are you as committed to managing my symptoms as you are to reducing my risk of cirrhosis?

'If you feel that your symptoms are not being taken seriously enough or being ignored by your clinicians then you are not receiving the best quality treatment. 'The main symptoms of PBC are fatigue, poor memory, itch and dry eyes and there are highly effective treatments for a number of these symptoms. Where there's a will there's a way.'

QUESTION FOR YOUR DOCTOR:
I am suffering from PBC symptom/s. What can we do to make it/them more manageable?

Patient tip:

There are a number of symptoms associated with PBC. Many patients remain for a long time completely asymptomatic whereas some can be affected in a number of different ways. We thoroughly believe that health care starts with self-care. There will be symptoms where your doctor can help and there will be symptoms that you can affect with your life choices, too. The key is informed decisions made in partnership with your clinician.

Once upon a time, what was called "brain fog" was dismissed as a symptom of PBC. Now we have an understanding that cognitive impairment can be a part of living with PBC and has a link with fatigue. There is research into more aspects of PBC such as Restless Leg Syndrome, etc which will help us refine our understanding of what it means to live with PBC and how we can best help patients.

Your symptoms are yours, and you are best placed to discuss them with your clinician and to make informed decisions about your care.

Guidelines 26 - 40

ITCH (PRURITUS): The Guidelines recommend that the following treatments be used for itch

i. Cholestyramine

ii. Rifampicin at a dose of 150 mg–300 mg daily with monitoring of liver bloods 6 weeks and twelve weeks after the start of the course. You need to have your blood checked 2-4 weeks after starting on this drug.

'If these treatments do not work, then you should return to your doctor and ask to be referred to a specialist clinic,' says Professor Jones. 'Treatment of symptoms is as important as reducing the risk of cirrhosis and symptoms should not be trivialised or ignored. Quality of life should be a very significant factor in any treatment plan for PBC.'

QUESTION FOR YOUR DOCTOR:
My itch has not improved with drug treatment. I would like to be referred to a specialist unit that deals with itching.

Patient tip:

"No," is not an acceptable answer. If medication for itch escalates beyond cholestyramine, then there needs to be detailed monitoring of the patient. This would be best done within a specialist unit with a working expertise of PBC.

FATIGUE: 'A major symptom of PBC, as the guidelines recognise, but it is worth keeping an open mind about this,' says Professor Jones. 'It is easy for a clinician to put your fatigue down to PBC and say there is nothing that can be done to help you, but actually there are lots of reasons for fatigue, including underactive thyroid, sleep disturbances, anaemia etc. The Guidelines make it clear that these should all be investigated and if necessary addressed as a separate issue.

'In my clinic we have a saying that the quickest way to treat fatigue is to diagnose a thyroid deficiency!

'However, if after thorough investigation, no other cause for the fatigue is found, then there are several ways to manage fatigue so that it minimises the effect on quality of life. Pace yourself and don't try to do too much. Fatigue is always worse later in the day so arrange appointments and other exertions as early as possible in the day. Finally, do your absolute best not to give up on work or social life as this can lead to isolation and depression and much reduced quality of life.'

QUESTION FOR YOUR DOCTOR:
Have you explored every other possibility for my fatigue apart from PBC including under active thyroid, anaemia etc?

Patient tip:

As Professor Jones states, the best way to manage fatigue is to find the cause and treat that cause, particularly if other conditions are the answer. In our many years as a Foundation, we have found that emotional, psychological and physical self-management can have a profound effect on fatigue: both for the negative and the positive. There is much we can do about fatigue and help to improve quality of life on a day-to-day basis living with PBC.

There is a cycle that incorporates our physical health, our mental state and our behaviours. It is all too easy to let our fatigue impact upon our emotional state, which then leads to unhelpful behaviours. We, as patients, can take control and begin to make the best possible decisions for ourselves and break this negative cycle. We can start, just one decision at a time, to make the best decision for us: eat the healthiest meal we can, do even just a little exercise, get the best night's sleep we can. Improve one thing at a time and you will see the positive impact it can have on your fatigue.

DRY EYES AND MOUTH (Sicca Syndrome): 'This can be a deeply unpleasant symptom and impact greatly on quality of life, yet it is sometimes easy for the clinician to see this as a relatively insignificant side effect,' says Professor Jones. 'Again, the Guidelines make it clear that if standard treatments fail, there are specialist clinics that can help and to which the patient should be referred.'

QUESTION FOR YOUR DOCTOR:
My dry eyes and mouth has not improved with drug treatments. I would like to be referred to a specialist, rheumatology clinic for further assessment.

Patient tip:

Again, no is not an acceptable answer. You know how each symptom affects you on a day-to-day basis. Either using the PBC Foundation app, or pen and pad, record the impact your symptoms have on a daily basis and use this information to advocate for your own care.
Hopefully, your clinician will have already tried first line therapies, as recommended in the guidelines, such as: artificial tears or artificial saliva; pilocarpine or cevimiline can be used if symptoms are persistent; oral hygiene advice should be given to those at risk of dental cavities; vaginal moisturisers may help but use of oestrogen creams should only be directed by primary care or specialist gynaecological services.

OSTEOPORIS: The Guidelines recommend that all patients with PBC should be considered at risk of osteoporosis and treated accordingly.

'Osteoporosis as a side effect of PBC should be treated in exactly the same way osteoporosis would be treated as an individual condition,' says Professor Jones.

'That is, a DEXA scan should be taken to establish a bone density baseline and Vitamin D and Calcium supplement used as a preventative measure. Lifestyle changes such as exercising more and giving up smoking can really help to improve the disease outlook. '

QUESTION FOR YOUR DOCTOR:
Do I have osteoporosis? If not, I would like a baseline DEXA scan for future reference.

Patient tip:

Osteoporosis, and osteopenia, are very manageable with or without PBC. However, if you don't know you are affected, you cannot manage the condition. Again, this is where you can easily ask informed questions to ensure you have access to the best possible care for you.

The guidelines recommend that every patient should be considered for risk assessment for osteoporosis. That includes you.

FAT SOLUBLE VITAMIN MALABSORPTION: The guidelines confirm that this condition can occur in patients with PBC particularly those with prolonged jaundice.

'The best way to counter this is to assume this may happen to you at some point and to ensure you get vitamin A, D and E in the form of a good quality over the counter supplement,' says Professor Jones. 'There is no need to ask for tests to measure your levels of these vitamins as a good supplement will counter any malabsorption.'

HIGH CHOLESTEROL: 'Cholesterol can be elevated in patients with PBC, but it is usually good cholesterol which on its own does not indicate risk of heart disease,' says Professor Jones. 'Raised 'bad' cholesterol should be treated in exactly the same way as if it were an individual condition'.

QUESTION FOR YOUR DOCTOR:
If I have high cholesterol is it bad or good cholesterol?

WATCHING YOUR PBC

Guidelines 41 – 47

'The really good news is that most people with PBC if they are diagnosed early and treated correctly with the optimum amount of Urso, will not go on to develop cirrhosis, ' says Professor Jones. 'Very few people with PBC will need a liver transplant. This is particularly true as awareness, diagnosis and treatment improve over time.'

The Guidelines note that some Urso non-responders may be at increased risk of cirrhosis and, as already discussed, this can be diagnosed with a fibroscan and ELF and ALT blood tests (not a liver biopsy). Thereafter the Guidelines recommend that you should be offered a regular ultrasound to check on activity and endoscopy to check on the blood vessels around the liver.

QUESTION FOR YOUR DOCTOR:
Do I need screening for cirrhosis complications and would it be useful for me to have a fibroscan?

Patient tip:

The guidelines recommend a "Structured life-long follow-up, recognising that patients have different disease courses, and may require varied levels of attention." This means that decisions made about your care need to take into account your circumstances. It is important to recognise the increased risk of Urso non-responders, length of time diagnosed, and age/sex of the patient when looking at a particular care pathway.

If we can help you in this conversation with your clinician, then do contact us to discuss your particular circumstances and how you can best move forward with your PBC care.

The Guidelines confirm that liver transplants are usually considered for patients whose bilirubin is 50 μmol/L or 3mg/dl or above at any point.

'If this number is reached this should be a trigger for referral to a liver transplant unit without delay,' says Professor Jones. 'Most patients who have a liver transplant do very well although a small number can develop PBC again. They can be treated as per the guidelines above as if they had just been diagnosed.'

QUESTION FOR YOUR DOCTOR:
Do I have a bilirubin level of over 50 μmol/L or 3 mg/dl? If so I wish to be referred to a liver transplant unit immediately.

Patient tip:

Usually with PBC, bilirubin tends to rise in a gradual way. If you are not responding to Urso and your counts are rising uncontrollably, we would hope you have been referred to a specialist liver unit already. However, if this has not happened and your bilirubin does reach 50 μmol/L or 3 mg/dl, this is an important trigger to being referred to a specialist liver transplant unit.

OWNING YOUR PBC

'PBC is a perfectly treatable condition which, for the majority for patients, if diagnosed early and currently managed will result in no reduction of lifetime survival or in increase in associated disease risk,' says Professor Jones.

'The fantastic work carried out by the PBC Foundation and other patient groups have continued to champion best treatment for their members by raising awareness of the disease both amongst clinicians and the general public. Perhaps most importantly the Foundation have provided their members with high quality information and support empowering them to manage their own treatment.

'After all, the best person to manage your treatment is you. And now, with the publication of these Guidelines, and the support of the PBC Foundation, you can drive your own treatment pathways and ensure that you receive the best possible care.

'Own your PBC rather than letting your PBC own you.'

QUESTION FOR YOUR DOCTOR:
Can I give you a link to the EASL PBC Guidelines download?

https://www.easl.eu/medias/cpg/Primary%20biliary%20cholangitis/English-report.pdf

Patient tip:

As Professor Jones states above, you are your own best advocate. This document is designed to stand alone and to bring you some of the most important aspects of the EASL guidelines in a way that helps you advocate for your own best care within your medical system. We hope that this empowers you to ask, in a respectful way, to be an active partner and to ensure you encounter best practice wherever possible.

You can offer your doctor the link to these guidelines. You can be an informed part of the decision making process when it comes to your care. You can be an active part of your own care, not only by self-managing but by ensuring you are involved.

If we can help you in any way, do contact us and we shall do our utmost to assist you in any way we can.

Guideline 47 "suggests that patients with PBC should be informed of the support available from patient support groups, including access to patient education material."
This is an important guideline, and one that sets a precedent for other guidelines in other fields also. This document would count as patient education material.

The PBC Foundation supports patients in 76 countries around the world, with our information available in 19 languages. You can find our information at:

www.pbcfoundation.org.uk

Some other organisations listed within the guidelines are below:

Austria: http://www.gesundeleber.at

France: http://www.albi-france.org

Germany: http://www.leberhilfe.org

Italy: http://www.fondazionefegato.it

The Netherlands: http://www.leverpatientenvereniging.nl

Norway: https://www.fal.link

Spain: http://www.albi-espana.org

Wherever in the world you are, you have the right to free, accurate and up-to-date information with regards to PBC.

We hope this document helps you in achieving that.

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Support for Life

For further information, please contact:
PBC Foundation (UK) Ltd
2 York Place, Edinburgh, EH1 3EP
Telephone: 0131 556 6811
Fax: 0131 556 8488
Email: info@pbcfoundation.org.uk
Website: www.pbcfoundation.org.uk

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